Family Carers' Experiences of Caring for a Person with Intellectual Disability

FINAL REPORT

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Glossary of Terms

AAPR	American Association of Retired Persons
ANOVA	Analysis Of Variance
ASD	Autism Spectrum Disorder
CNS	Clinical Nurse Specialist
CSO	Central Statistics Office
CSRI	Client Services Receipt Inventory
DA	Disability Allowance
DCA	Domiciliary Care Allowance
DCD	Developmental Coordination Disorder
DSP	Department of Social Protection
FCI	Family Carers Ireland
FSS	Family Support Scale
GHQ	General Health Questionnaire
GP	General Practitioner
HREC	Human Research Ethics
ID	Intellectual Disability
IQR	Interquartile Range
MCI	Mild Cognitive Impairment
Mdn	Median
NAC	National Alliance for Caregiving
NDA	National Disability Authority
NDSIG	National Disability Strategy Implementation Group
NFVB	National Federation of Voluntary Bodies
NIDD	National Intellectual Disability Database
NVIVO	Nudist Vivo version 9.0
RSA	Resilience Scale for Adults
SCS-R	Social Connectedness Scale-Revised
SPSS	Statistical Package for Social Sciences

Executive Summary

Introduction

There are almost 58,000 people living with an intellectual disability in Ireland[1] and it is estimated that around two-thirds are cared for at home by their families.[2] Family carers are an important resource in the provision of care for people with intellectual disability in Ireland and the Department of Health (DoH) has begun to acknowledge this with the publication of the 'National Carers' Strategy'.[3] While some families struggle with caregiving, others thrive and adapt well to caregiving strains and responsibilities. These families may be considered 'resilient', that is, they are able to overcome, resist, or adapt to the physical and psychological demands of caring.[4]

Several studies have reported that families with a person with intellectual disability tend to have lower levels of resilience than those found in the general population.[5,6,7] Individual characteristics such as age, gender, caring workload, and care-recipient dependency can contribute to resilience,[8,9,10,11]

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[1] Central Statistics Office (CSO) (2012a) **Profile 8. Our Bill of health**. Dublin: The Stationary Office.

[2] Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., *et al.* (2014). **Mapping the National Disability Policy Landscape.** Dublin: School of Social Work and Social Policy, Trinity College.

[3] Department of Health (DoH) (2012a) **The National Carers' Strategy: Recognised, Supported, Empowered**. Dublin: The Stationary Office.

[4] Herrman, H., Stewart, D., Diaz-Granados, N., Berger, E., Jackson, B. and Yuen T. (2011) What is resilience? **Canadian Journal of Psychiatry**, 56(5), 258–265.

[5] Baxter, C., Cummins, R.A. and Yiolitis, L. (2000) Parental stress attributed to family members with and without disability: A longitudinal study. **Journal of Intellectual and Developmental Disability**, 25, 105–118.

[6] Baker, L.B., Blacher, J. and Olsson, M.B. (2005) Preschool children with and without developmental delay: Behaviour problems, parents' optimism and wellbeing. **Journal of Intellectual Disability Research**, 49, 575–590.

[7] Wong, P.K.S. and Lam, T.L. (2015) Enhancing the resilience of parents of adults with intellectual disabilities through volunteering: An exploratory study. **Journal of Policy and Practice in Intellectual Disabilities,** 12 (1), 20–26.

[8] Bekhet, A.K., Johnson, N.L. and Zauszniewski, J.A. (2012) Resilience in family members of persons with autism spectrum disorder: a review of the literature. **Issues in Mental Health Nursing**, 33 (10), 650–656.

[9] Grant, G., and Whittell, B. (2000) Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the lifespan. **Journal of Applied Research in Intellectual Disabilities**, 13 (4), 256–75.

[10] Llewellyn, G., McConnell, D., Gething, L., Cant, R. and Kendig, H. (2010) Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. **Research in Developmental Disabilities**, 31 (6), 1176-1186.

[11] Bayat, M. (2007) Evidence of resilience in families of children with autism. **Journal of Intellectual Disability Research***,* 51, 702–714.

as well as social factors such as family solidarity, social connectedness, and social support.[12,13,14] Environmental factors such as formal supports and community resources can also play an important role in resilience.[15,16]

According to national census data, 187,112 people provide unpaid care to others, culminating in 327 million hours of care being provided each year. The majority of these carers are female, married, and aged between 40 and 59 years.[17] Traditional family caregiving is changing and an increasing number of family carers are becoming 'compound carers', that is, carers who provide care to multiple care-recipients. Compound carers have competing caregiving demands and have the added challenges associated with prioritising care needs. Families are becoming smaller with fewer family members available to provide care and women are waiting longer before having children, which means that an increasing number of carers are finding themselves in the sandwich generation, providing care for their young children as well as for ageing parents. People with intellectual disability are now also living longer with some families becoming 'two generation elderly families'.[18] In some cases, a person with intellectual disability may be providing care to their elderly parent or may even outlive their parents.[19] Under these circumstances, there appears to be a growing number of siblings who assume the role of carer for a person with intellectual disability when a parent passes away.[20]

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[12] Grant, G., Ramcharan, P. and Flynn, M. (2007) Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. **Journal of Applied Research in Intellectual***,* 20 (6), 563–575.

[13] Gerstein, E.D., Crnic, K.A, Blacher, J. and Baker, B.L. (2009) Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. **Journal of Intellectual Disability Research,** 53 (12), 981–997.

[14] Bekhet, A.K., Johnson, N.L. and Zauszniewski, J.A. (2012) Resilience in family members of persons with autism spectrum disorder: a review of the literature. **Issues in Mental Health Nursing**, 33 (10), 650–656.

[15] Ouellette-Kuntz, H., Blinkhorn, A., Rouette, J., Blinkhorn, M., Lunsky, Y. and Weiss, J. (2014) Family resilience: An important indicator when planning services for adults with intellectual and developmental disabilities. **Journal on Developmental Disabilities**, 20 (2), 55–66.

[16] Pottie, C.G. and Ingram, K.M. (2008) Daily stress, coping, and well-being in parents of children with autism: A multilevel modelling approach. **Journal of Family Psychology***,* 22 (6), 855–864.

[17] Central Statistics Office (CSO) (2012a) **Profile 8. Our bill of health**. Dublin: The Stationary Office.

[18] McCallion, P., McCarron, M. and Force, L.T. (2005) A measure of subjective burden for dementia care: The caregiving difficulty scale- Intellectual Disability. **Journal of Intellectual Disability Research,** 49 (5), 365–371.

[19] Green, S.E. (2013) Convergent caregiving: Exploring eldercare in families of children with disabilities. **Journal of Loss and Trauma**, 18 (4), 289–305.

[20] Tebes, J.K. and Irish, J.T. (2000) Promoting resilience among children of sandwiched generation caregiving women through caregiver mutual help. **Journal of Prevention and Intervention in the Community**, 20 (1-2), 139–158.

This study aims to gain a better understanding of family carers' experiences of caring for a person(s) with intellectual disability, with a focus on the factors that enhance family resilience.

Objectives

The objectives of the study are to:

- Examine current support structures within families with a person with intellectual disability.
- Measure resilience among family carers of a person with intellectual disability.
- Identify factors that promote or hinder resilience within families with a person with intellectual disability.
- Examine social connectedness among family carers of a person with intellectual disability.
- Explore the compound carer's experience of providing care for a person with intellectual disability, while also providing care for another person(s).

Methods

This study comprised two phases. Phase 1 involved an anonymous postal survey of 600 family carers in receipt of a Carer's Allowance for the care of a relative with intellectual disability, aged 16 years and older. Each carer received a letter from the Department of Social Protection (DSP) notifying them of the study and encouraging them to participate. A questionnaire and stamped addressed envelope was posted to carers and, approximately a week later, carers received a letter reminding them to return the questionnaire and thanking those who had done so already. The questionnaire collected information about carers' demographics, their caregiving experience, caregiving supports, and about their relative with intellectual disability. Data was analysed using a Statistical Package for Social Sciences (SPSS) version 20 and both descriptive and inferential statistical tests were used in the analysis.

Phase 2 consisted of in-depth telephone interviews with compound carers who, in addition to their relative with intellectual disability, provided regular unpaid care to a second person requiring full-time care. Participants were recruited via the postal survey in Phase 1. Interviews lasted between 40 and 75 minutes and were audio recorded and transcribed verbatim. The data was managed using NVivo 9.0 software and analysed using thematic content analysis.[21]

[21] Creswell, J.W. (2013) **Qualitative, quantitative, and mixed methods approaches.** London: Sage Publications.

Key Findings

Phase 1

A total of 247 carers participated in the survey, yielding a 41% response rate. Respondents were aged 24 to 86 years, with a mean age of 52 years (*SD* = 9.8). Respondents were predominantly female (81.1%), Irish (93.5%), married or in a civil partnership (53%), and had been caring for an average of 15 years. The vast majority of carers (83.5%) were a parent to a person with intellectual disability and about one in ten were a sibling carer (10.6%). Over a quarter of respondents (26.3%) met the study's criteria of compound carer indicating that, in addition to their relative with intellectual disability, they provided regular unpaid care to another person.

Care-recipients with intellectual disability were aged 16 to 86 years, with an average age of 19 years. Care-recipients had mainly a mild to moderate intellectual disability and had relatively low levels of challenging behaviour.

Survey data suggested that carers were relatively resilient and generally managed well, adapting to their caregiving roles and responsibilities. However, four out of ten carers (40.8%) scored above the threshold for psychological distress and, while two thirds of carers (66.0%) described their general health as good, very good or excellent, the remaining described their health as poor or fair. While the majority of carers felt a sense of belonging and scored high in social connectedness, over a quarter reported low social connectedness. Some gaps in services were identified, particularly in relation to access to crisis respite care and alternative therapies.

A number of statistically significant factors were associated with low carer resilience including being a compound carer, living with the care-recipient with intellectual disability, high levels of psychological distress, poor/fair self-reported general health, and low levels of social connectedness. Findings also revealed that low carer resilience was related to high levels of challenging behaviour in care-recipients as well as low levels of support from family, other informal supports, and formal supports.

Phase 2

Fourteen compound carers (four males and ten females) participated in telephone interviews. Participants were between the ages of 38 and 65 years, and were classified into three distinct compound carer categories. Six participants were 'parental compound carers' and provided care to a child with intellectual disability, as well as to another family member in need of full-time care. Four participants were 'sandwich compound carers' and provided care to a child with intellectual disability, as well as to a dependent parent. Finally, four participants were 'sibling compound carers' and provided care to a brother or sister with intellectual disability, as well as to another dependent relative.

An analysis of the interview data resulted in the following three main themes: 'Divisions of Compound Caring', 'Learning and Transitioning', and 'Maintaining and Sustaining Continuity of Care'. The findings suggest that individual carers approached compound caregiving differently. While some carers tried to balance their caregiving roles separately, others fully immersed themselves and merged their compound caregiving responsibilities. Participants also described their experiences of transitioning and adapting to their compound caregiving situation. Some carers spoke about being thrown in 'at the deep end', however, most carers demonstrated high levels of resilience and acceptance, indicating an ability to adapt over time to their compound caregiving roles. The findings also showed that participants expressed a desire to maintain stability and continuity in the care that they provided. This meant that many carers adopted an insular approach to care, to prevent disruptions to the family's routine and care systems. Having refuge outside of caregiving was deemed important by carers in enabling them to continue their compound caregiving role.

Relevance to the Literature

This study provides important information about family carers and their experiences of caregiving for a person with intellectual disability. Findings suggest that a higher number of carers of a person with intellectual disability are female (81.1%), when compared with national carer data (61.2%),[22] and that carers tended to have lower levels of education than the general population.[23] The difference in levels of educational attainment may be as a consequence of carers' commitment to their caregiving role. An analysis of the data also revealed that over a third of respondents indicated that they were single, separated, divorced or widowed, suggesting that a relatively large proportion of respondents were lone carers. These findings are consistent with those reported by Barron and colleagues (2006), and are factors that need to be taken into account when developing support services.[24]

In this study, just over a quarter of carers were caring for a person with intellectual disability, in addition to another relative who required full-time care and attention. This proportion is somewhat lower when compared to other studies such as that undertaken by Perkins and Haley (2010), which reported that over a third of carers (37%) provided care to a second person. This discrepancy may be attributable to differences in the definition used for 'compound carer'. Sibling carers accounted for 10% of survey respondents and, as suggested by other research studies, this

[22] Central Statistics Office (CSO) (2012a) **Profile 8. Our bill of health**. Dublin: The Stationary Office.

[23] Central Statistics Office (CSO) (2012b) **Profile 9. What we know**. Dublin: The Stationary Office.

[24] Kelly F., Craig S., McConkey R. and Mannan H. (2009) Lone parent carers of people with intellectual disabilities in the Republic of Ireland. **British Journal of Learning Disabilities**, 37, 265–270.

percentage is likely to increase as people with intellectual disability age.[25,26] Consistent with the literature on sibling carers, this study found that sisters were more likely to provide care to their sibling with intellectual disability than brothers.[27,28]

The majority of care-recipients with intellectual disability in this study were male (71.1%), which is a much higher proportion than that recorded on the National Intellectual Disability Database (NIDD) (58.2%).[29] Consistent with the NIDD records, care-recipients had mainly mild to moderate intellectual disability.

The study findings showed that while most carers were in receipt of a range of services, some have not received the services they require. For example, just over half of the respondents who indicated that they required crisis respite care in the previous six months, did not receive the service. There has been a marked increase in the demand for respite services;[30] however, there has been a decline in the provision of crisis and planned respite care in recent years.[29] In addition, more than one in five carers indicated that their relative with intellectual disability required alternative therapies (e.g. sensory therapy) in the previous six months, however, the majority of whom did not receive this service. There were also unmet service needs in areas such as psychological and counselling services, dietician services, home-based respite services, and occupational therapy. According to Kelly (2015), there has been a significant demand for enhanced multidisciplinary support services. As shown in this study, low levels of informal support were associated with low levels of resilience. Therefore, ensuring that families are appropriately supported is important in maintaining family resilience.

[25] Brennan, D., Murphy, R., McCallion, P., Griffiths, M. and McCarron, M. (2016) **Understanding family strategies that enable long term and sustainable home environments for older people with intellectual disability. Executive Summary.** Dublin: Trinity College Dublin.

[26] IDS-TILDA (2016) IDS-TILDA Valuing carers' involvement. Accessed on 20 June from: http://www.idstilda.tcd.ie/info/

[27] Orsmond, G., and Seltzer, M. (2000) Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. **American Journal on Mental Retardation**, 105, 486–508.

[28] Coyle, C., Kramer, J., and Mutchler, J.E. (2014) Aging together: Sibling carers of adults with intellectual and developmental disabilities. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (4), 302–312.

[29] Kelly, C. (2015) **HRB Statistics Series 28 Annual report of the National Intellectual Disability Database committee 2014.** Dublin, Ireland: Health Research Board.

[30] McConkey R., Kelly F., Mannan H. and Craig S. (2010) Inequalities in respite service provision: insights from a national, longitudinal study of people with intellectual disabilities. **Journal of Applied Research in Intellectual Disabilities**, 23, 85–94.

Despite previous studies reporting that parents of children with intellectual disability tend to experience lower levels of resilience than other parents,[31,32,33] in the present study, the survey respondents were found to be relatively resilient. However, two fifths of respondents scored above the threshold for poor psychological distress (40.8%), which is a much higher proportion than that found among the general population (12%).[34] Furthermore, a third of carers reported poor general health and a quarter reported low levels of social connectedness. Chadwick and colleagues (2013) discuss the propensities of families of people with intellectual disability and highlight their ability to adjust to caregiving situations over time.

Several factors were found to be associated with low carer resilience in this study. Carer psychological health was among the individual factors associated with resilience. Carers who experienced poor psychological wellbeing were more likely to have lower levels of resilience. This finding is consistent with previous studies that have reported that good mental health in parents was positively associated with family resilience.[35] Other individual factors included being a compound carer, poor/fair self-reported general health, living with the care-recipient with intellectual disability, and higher levels of challenging behaviour exhibited by the care-recipient.

Social factors associated with low resilience included low levels of family support and low levels of social connectedness. Having strong familial relationships is considered a key protective factor in maintaining resilience,[36,37,38] particularly if families can pool together their resources, maintain good communication, stay connectedness, and

[31] Baxter, C., Cummins, R.A. and Yiolitis, L. (2000) Parental stress attributed to family members with and without disability: A longitudinal study. **Journal of Intellectual and Developmental Disability**, 25, 105–118.

[32] Baker, L.B., Blacher, J. and Olsson, M.B. (2005) Preschool children with and without developmental delay: Behaviour problems, parents' optimism and wellbeing. **Journal of Intellectual Disability Research**, 49, 575–590.

[33] Wong, P.K.S. and Lam, T.L. (2015) Enhancing the resilience of parents of adults with intellectual disabilities through volunteering: An exploratory study. **Journal of Policy and Practice in Intellectual Disabilities,** 12 (1), 20–26.

[34] Tedstone Doherty, D., Moran, R. and Kartalova-O'Doherty, Y. (2008) **Psychological distress, mental health problems and use of health services in Ireland. HRB Research Series 5**. Dublin: Health Research Board.

[35] Choi, E.K. and Yoo, I.Y. (2015) Resilience in families of children with Down syndrome in Korea. **International Journal of Nursing Practice**, 21, 532–541.

[36] Gerstein, E.D., Crnic, K.A, Blacher, J. and Baker, B.L. (2009) Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. **Journal of Intellectual Disability Research,** 53 (12), 981–997.

[37] Walsh, F. (2003) Family resilience: a framework for clinical practice. **Family Process**, 42 (1), 1-18.

[38] Peer, J. W. and Hillman, S.B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (2), 92–98.

share caregiving commitments.[39,40,41] Previous studies have also highlighted the importance of maintaining stable social networks in maintaining family resilience.[42] For example, social support can be sought from partners, family, extended family, friends and neighbours in the community, faith-based services, as well as networks developed through working and volunteering.[43,44,45,46]

Environmental factors associated with resilience tend to be in relation to formal supports and services. In this study, low levels of formal supports were related to low levels of resilience in carers. A US study found that better access to services resulted in greater levels of well-being in carers and an increase in their perceived ability to cope.[47] In addition, formal supports can provide reassurance to carers by helping them to increase their confidence,[42] and promote resilience.

More than one in four carers who responded to the postal survey indicated that they were a compound carer, meaning that they provided care to a second dependent person, in addition to their relative with intellectual disability for whom they received a carer's allowance. The majority of these compound carers were also providing care to an elderly parent or another child. The findings from the interview data in phase 2 of the study highlighted the diverse nature of compound caring situations, which included parental, sibling and sandwich compound caregiving. Similar caregiving

[39] Choi, E.K. and Yoo, I.Y. (2015) Resilience in families of children with Down syndrome in Korea. **International Journal of Nursing Practice**, 21, 532–541.

[40] Bekhet, A.K., Johnson, N.L. and Zauszniewski, J.A. (2012) Resilience in family members of persons with autism spectrum disorder: a review of the literature. **Issues in Mental Health Nursing**, 33 (10), 650–656.

[41] Greeff, A.P. and Nolting, C. (2013) Resilience in families of children with developmental disabilities. **Family Systems and Health,** 31 (4), 396-405.

[42] Peer, J. W. and Hillman, S.B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (2), 92–98.

[43] Richardson, E.W. and Stoneman, Z (2015). The road to membership: The role of resilience in seeking and maintaining membership in a faith community for families of children with disabilities. **Journal of Disability and Religion**, 19 (4), 312–339.

[44] Llewellyn, G., McConnell, D., Gething, L., Cant, R. and Kendig, H. (2010) Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. **Research in Developmental Disabilities**, 31 (6), 1176-1186.

[45] Hall, H.R. and Graff, J.C. (2011) The relationships among adaptive behaviours of children with autism, family support, parenting stress, and coping. **Issues in Comprehensive Pediatric Nursing**, 34 (1), 4–25.

[46] Rozario, P.A., Morrow-Howell, N. and Hinterlong, J.E. (2004) Role enhancement or role strain. Assessing the impact of multiple productive roles on older caregiver well-being. **Research in Aging**, 26 (4), 413–418.

[47] Holl, E. and Morano, C.L. (2014) Supporting the next generation of caregivers: Service use and needs of adult siblings of individuals with intellectual disability. **Inclusion**, 2 (1), 2–6.

situations have been reported in the literature.[48,49,50,51] The interviews highlighted the different approaches adopted by carers to compound caregiving. While some carers separated their caregiving roles, others amalgamated their responsibilities and integrated the roles into their own life. Similar to findings from previous studies, this study suggested that carers were sometimes forced to prioritise their caregiving responsibilities.[52]

Data analysis also revealed the processes carers engaged in when transitioning to the role of compound carer. Becoming a compound carer can sometimes occur unexpectedly, and with no formal arrangements in place, such as when a parent passes away and another child has to take over the care of their sibling.[49,53] Participants spoke then about their readiness, preparedness, and acceptance of taking on multiple caregiving roles, regardless of the changes in family structures and care systems. Also evident from the interview data, was a sense of familial commitment and solidarity. These family qualities have been shown to promote positive intergenerational exchanges in family caregiving structures.[48] Maintaining continuity of care for their relative with intellectual disability was important to participants, and consequently, many adopted an insular approach to caregiving, so as not to disrupt the established routines and the current provision of care. A self-reliance style of caregiving has been noted in other studies, whereby family carers tend to overcome the challenges of compound caregiving as best they can themselves, rather than seek additional support.[54] This response may also be attributable to the transient nature of compound caregiving.[54]

Key Implications for Policy and Practice

- As two-fifths of carers reported levels of psychological distress that were more than three times higher than levels found among the general public, family carers

[48] Grundy, E. and Henretta, J.C. (2006) Between elderly parents and adult children: A new look at the intergenerational care provided by the sandwich generation. **Ageing and Society**, 26 (5), 707–722.

[49] Tebes, J.K. and Irish, J.T. (2000) Promoting resilience among children of sandwiched generation caregiving women through caregiver mutual help. **Journal of Prevention and Intervention in the Community**, 20 (1-2), 139–158.

[50] Perkins, E.A., and Haley, W.E. (2010) Compound caregiving: When lifelong caregivers undertake additional caregiving roles. **Rehabilitation Psychology**, 55 (4), 409–417.

[51] Dew, A., Llewellyn, G., and Balandin, S. (2004) Post-parental care: A new generation of sibling-carers. **Journal of Intellectual and Developmental Disability**, 29, 176–179.

[52] Kwok, H. (2006) The son also acts as major caregiver to elderly parents: A study of the sandwich generation in Hong Kong. **Current Sociology,** 54 (2), 257–272.

[53] Coyle, C., Kramer, J., and Mutchler, J.E. (2014) Aging together: Sibling carers of adults with intellectual and developmental disabilities. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (4), 302–312.

[54] Perkins, E.A. (2010) The compound caregiver: A case study of multiple caregiving roles. **Clinical Gerontologist**, 33, 248–254.

need to be supported to maintain good mental health. Community-based health and social care professionals need to engage more with carers and provide the necessary supports to help prevent their mental health from deteriorating.

- One in four carers reported low social connectedness, therefore carers should be supported and encouraged to have greater societal participation and integration within their communities through engagement with activities such as work and/or study outside the home, as well as with carer support groups.
- Higher levels of challenging behaviours exhibited by a person with intellectual disability was shown to negatively impact carer resilience, therefore families need access to interventions and education, and be supported in the management of challenging behaviours exhibited by their relative. Educational programmes and information should be available to parents and other family members on non-aversive strategies to promote positive behaviour, as well as on approaches to managing challenging behaviour.
- As compound carers experienced lower levels of resilience and social connectedness than non-compound carers, their needs and caregiving situation should be assessed individually, taking into account their unique caregiving circumstances. Service providers and policies also need to acknowledge and recognise that families have diverse needs and 'one size' does not fit all.
- Perceived helpfulness of support services was positively correlated with carer resilience, therefore carers should be included and consulted as part of service evaluations, so that resources can be appropriately tailored, allocated, and best utilised by families.
- In-home supports such as home-based respite, home-based therapies, and home help require the allocation of greater resources so that regular uninterrupted care can be provided by carers to a relative with intellectual disability and the care can continue to be maintained and sustained, amidst changes to traditional family caregiving.

Next Steps

This study comprised a cross-sectional survey of family carers of a person with intellectual disability, who were in receipt of a social welfare payment for the care they provided. This is only a subset of carers and further research is needed to examine the experiences of other cohorts of carers, including those who do not meet the eligibility criteria for a Carer's Allowance or who combine full-time employment with care of a relative with intellectual disability. Longitudinal data from multiple perspectives would also provide invaluable information on the changing care needs of families over time. Very little research has been conducted to date with carers who have multiple caregiving roles. Therefore future studies should collect both qualitative and quantitative information on compound carers, in order to examine more closely the changing nature of caregiving roles assumed by family

carers, the unique caregiving situations and the challenges associated with caring for more than one person.

Conclusions

This study examined the experiences of carers who were in receipt of a Carer's Allowance for the care of a relative with intellectual disability. The study's findings revealed that while carers were relatively resilient this may come at a personal cost, as high levels of psychological distress were found in two-fifths of carers and a third of carers reported having poor or fair health. Furthermore, over one in four carers were considered to have low levels of social connectedness. The study findings highlighted several factors that were related to low carer resilience including co-residing with their relative with intellectual disability, being a compound carer, having high levels of psychological distress, and low levels of social connectedness, and poor general health. High levels of challenging behaviour exhibited by their relative with intellectual disability, as well as low levels of family, social, and formal supports were also associated with poor carer resilience. Compound caregiving will likely become more prevalent in years to come and carers will need support in transitioning and sustaining the compound caregiving role.

Findings from this study provide a better understanding of the unique caregiving circumstances and structures within families caring for a person with intellectual disability. The factors that can lead to low carer resilience have been identified and can therefore, be targeted in order to maximise and sustain resilience among family carers. This approach can help to ensure that, with the support of professionals, policies, and services, family caregiving can continue to be a valuable resource in society. The study findings can be used to inform policies and services so that appropriate and suitable supports can be developed to meet the needs of people with intellectual disability and their families.

Chapter 1: Introduction

This chapter summarises the Irish context for family caregiving, particularly in relation to family carers of a person with intellectual disability*. Relevant carer and disability policies are outlined. The chapter also presents the aim and objectives of the study, and gives a brief overview of the study design, data collection methods and approaches to data analysis.

1.1 Family Caregiving in Ireland

The most recent census defines a 'carer' as a person who provides 'regular unpaid, personal help for a friend or family member with a long-term illness, health problem or disability' (p.127).[55] Statistics show that a growing proportion of the Irish population are providing regular care to friends and relatives. In 2002, 148,754 people reported that they provided unpaid care. This figure grew to 160,917 in 2006, and in 2011 182,884 people indicated that they provided unpaid care.[55] This Census data suggests a 23% rise in the number of informal carers since 2002 with the current number of unpaid carers (aged 15 years and older) now accounting for 4.1% of the Irish population. This percentage is somewhat lower when compared to other nation states such as Northern Ireland, where almost three times the proportion of the population (11.8%) have identified themselves as carers[56], or in the U.S. where 18.2% self-reported that they were caregivers.[57] This difference may be attributable to the wording used in the survey questions, or due to contrasting cultural views of the term carer and a lack of self-identification among carers.

Figures show that a substantial 327 million hours of care are provided by unpaid carers in Ireland each year.[55] Most of these carers are female, aged between 40 and 59 years, married and live in rural areas.[55] The majority of carers (58%) provide between one and fourteen hours of care per week and approximately one fifth of carers (21%) provide care for 43 hours or more on a weekly basis. Almost 60% are reported to be in employment.

Changes to family structures are having significant consequences for the family caregiving situation. One third of families in Ireland are now considered to be outside

* Throughout this report, 'intellectual disability' refers to a person with intellectual disability and/or autism.

[55] Central Statistics Office (CSO) (2012a) **Profile 8. Our Bill of health**. Dublin: The Stationary Office.

[56] Care Alliance Ireland (CAI) (2015a) **Family caring in Ireland.** Dublin: CAI.

[57] AARP/NAC (2015) **Caregiving in the U.S. 2015.** US: AARP Public Policy Institute and National Alliance of Caregiving.

the 'traditional model'.[58] Due to the decline in fertility rates, and the increase in the number of women in the workforce, families are now smaller with fewer individuals available to provide care.[53] Women are now waiting longer before having a family and consequently an increasing number of carers find themselves in the sandwich generation, that is, caring for their own young children while also providing care to elderly parents. The nature of this caregiving situation means that carers will encounter circumstances unique to their caregiving role, such as having to balance competing caregiving demands and prioritize the care of their children over the care of their elderly parents.[59] Another way in which family structures have begun to change and impact family care, is the increased number of lone parents caring for a person with intellectual disabilities, particularly, those caring for an individual aged 20 years and younger with a mild intellectual disability.[60]

1.2 Intellectual Disability and Family Caregiving

According to the 2011 census, there are 57,709 people living with intellectual disability in Ireland.[61] This figure accounts for 1.3% of the population. The census data shows that the incidence of intellectual disability is more common among males and that the majority of people with intellectual disability suffer from other difficulties such as problems with learning, remembering or concentrating, and one in three have a psychological disability. Consequently many experience difficulties with working, attending school or college, and spending time independently outside of the home.[61] Autism is commonly associated with intellectual disability[62] and, while there is no census data available in Ireland on the number of those living with autism, a recent research study estimated that as many as 50,000 people are affected by autism.[63]

Since 1995, a database of all persons in receipt of intellectual disability services has been in operation in the Republic of Ireland. The data from the NIDD indicates that

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[58] Lunn, P. and Fahey, T. (2011) **Households and family structures in Ireland: A detailed statistical analysis of Census 2006**. Dublin: The Economic and Social Research Institute and the Family Support Agency.

[59] Kwok, H. (2006) The son also acts as major caregiver to elderly parents: A study of the sandwich generation in Hong Kong. **Current Sociology,** 54 (2), 257–272.

[60] Kelly F., Craig S., McConkey R. and Mannan H. (2009) Lone parent carers of people with intellectual disabilities in the Republic of Ireland. **British Journal of Learning Disabilities**, 37, 265–270.

[61] Central Statistics Office (CSO) (2012a) **Profile 8. Our Bill of health**. Dublin: The Stationary Office.

[62] Hoekstra, R.A., Happé, F., Baron-Cohen, S. and Ronald, A. (2009) Association between extreme autistic traits and intellectual disability: insights from a general population twin study. **The British Journal of Psychiatry**, 195 (6), 531–536.

[63] Sweeney M.R., Staines A. and Boilson A. (2016) **Autism Counts: A report on Autism Spectrum Disorder prevalence estimation in the Republic of Ireland.** Dublin City University: School of Nursing and Human Sciences.

27,515 people with intellectual disability are registered and in receipt of formal services.[64] The majority are male (58.2%) and between the ages of 35 to 54 years old (27.6%). A third (33%) have a mild intellectual disability, over two fifths (41%) have a moderate intellectual disability, 14.5% have a severe intellectual disability, 3.3% have a profound intellectual disability, and 8.4% are reported as unverified.[64] While two thirds of those availing of services are supported at home by their parents, siblings, relatives or foster parents,[65] little is known about the nature of the family care, supports, and the circumstances in which that care is being provided.

The increase in lifespan of people with intellectual disability,[64,65] together with changes in family structures, the landscape of traditional caregiving is also changing. An unprecedented longer life expectancy means that parents and family carers of people with intellectual disability are providing care for longer and some families may now become 'two generation elderly families' where both the family carer and the person with intellectual disability are over 60 years of age.[66] As carers grow older, they may develop health problems of their own and, in some cases, this may result in a reversal of roles, where the person with intellectual disability finds themselves providing the care for their primary family carer.[67,68]

Parents of children with intellectual disabilities assume a caregiving role from birth, but as their child grows older, there is an 'increasing likelihood that they may become caregivers to their own parents or other family members' (p. 248).[69] In some instances, it is a sibling who becomes the primary caregiver for his/her brother or sister with intellectual disability when a parent passes away. Siblings may find themselves trying to balance the constant demands of caring for their brother or sister with intellectual disability, while simultaneously trying to raise a young family of their own. Especially for older families, there are increased pressures to provide

[64] Kelly, C. (2015) **HRB Statistics Series 28 Annual report of the National Intellectual Disability Database committee 2014.** Dublin, Ireland: Health Research Board.

[65] Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., *et al.* (2014). **Mapping the National Disability Policy Landscape.** Dublin: School of Social Work and Social Policy, Trinity College.

[66] McCallion, P., McCarron, M. and Force, L.T. (2005) A measure of subjective burden for dementia care: The caregiving difficulty scale- Intellectual Disability. **Journal of Intellectual Disability Research,** 49 (5), 365–371.

[67] Green, S.E. (2013) Convergent caregiving: Exploring eldercare in families of children with disabilities. **Journal of Loss and Trauma**, 18 (4), 289–305.

[68] Care Alliance Ireland (CAI) (2015b) **Discussion Paper 2: Intellectual Disability, Caring and Role Reversal.** Dublin: CAI.

[69] Perkins, E.A. (2010) The compound caregiver: A case study of multiple caregiving roles. **Clinical Gerontologist**, 33, 248–254.

care for longer and to plan for the future care of their relative with intellectual disability.[70,71]

1.3 Irish Policy and Supports for Family Carers

Ireland has a number of structures in place within its health, social care, and welfare system to support informal carers. An explicit objective of the Irish health care system and Irish government policy is to ensure that carers are supported in their caring role. The Department of Health published the 'National Carers' Strategy', which provides recognition to family carers and acknowledges them as the 'backbone' of care provision in Ireland.[72] The strategy provides a roadmap for informal caregiving and aims to ensure that 'carers feel valued and supported to manage their caring responsibilities with confidence and empowered to have a life of their own outside of caring' (p. 3).[72] The strategy identifies 'a carer' as a person 'who is providing an ongoing significant level of care to a person who is in need of that care in the home due to illness or disability or frailty' (p. 8).[72] The 'National Carers' Strategy' was drafted in a climate of economic austerity, with a view to its measures being adequately funded in subsequent iterations. All major political parties have since committed to the implementation of a renewed and funded strategy.[73] The document sets out a number of priority areas, which include the following:

- Recognise the value and contribution of carers and promote their inclusion in decisions relating to the person that they are caring for.
- Support carers to manage their physical, mental and emotional health and well-being.
- Support carers to care with confidence through the provision of adequate information, training, services and supports.
- Empower carers to participate as fully as possible in economic and social life.

There have been several Irish policy documents published in recent years that focus on improving the lives of people with intellectual disability living at home in the community with their families. 'The National Disability Strategy Implementation Plan 2013-2015', prepared by the National Disability Strategy Implementation Group

[70] Gilbert, A., Lanskshear, G. and Petersen, A. (2008) Older family-carers' views on the future accommodation needs of relatives who have an intellectual disability. **International Journal of Social Welfare**, 17 (1), 54–64.

[71] Taggart, L., Truesdale-Kennedy, M., Ryan, A. and McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. **Journal of Intellectual Disabilities,** 16 (3), 217–234.

[72] Department of Health (DoH) (2012a) **The National Carers' Strategy: Recognised, Supported, Empowered**. Dublin: The Stationary Office.

[73] Family Carers Ireland (2016). **Summary of the Commitments made for Family Carers by Political Parties in Election 2016.** Dublin: Family Carers Ireland.

(NDSIG),[74] and 'The Value for Money and Policy Review of the Disability Services' in Ireland, published by the Department of Health,[75] frame the demographic shift that is occurring within families caring for persons with intellectual disability. These documents promote equality for people with intellectual disability with a particular emphasis on the collaboration of government, voluntary, and community sectors.[74,75]

Family carers are an important resource in the provision of care for persons with intellectual disability in Ireland, with over two thirds of those registered with the NIDD living at home.[76,77] However, according to Thompson and colleagues (2014)[78] and Linehan and colleagues (2014)[79], support for carers in their caring role is not in recognition of existing caring demands and expectations.[78,79] The current Vision Statement for Intellectual Disability in Ireland highlighted 'an absence of focus on family goals and the development of the families' capacities' (p. 7).[80] Such documents demonstrate that there is a lack of support and understanding of families where there is a person with intellectual disability.

In Ireland, financial supports are available to families caring for a person in need of full-time care. The DSP offers a Carer's Allowance to eligible carers over the age of 18 years. A family carer providing full-time care for a person with intellectual disability may apply for a Carer's Allowance, currently set at €204 weekly for a carer under 66 years and €242 for those over 66 years. This is a means-tested form of income support available to carers of individuals who require full-time care and attention. If care is being provided to a second person, then the payment is increased by 50%. A half-rate Carer's Allowance is available to carers who are in receipt of another social welfare payment (e.g. one-parent family payment). This payment is also means-tested. Anyone who receives a Carer's Allowance is permitted to work

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[74] National Disability Strategy Implementation Group (NDSIG) (2013) **National Disability Strategy Implementation Plan 2013-2015**. Dublin, Ireland: Department of Justice and Equality, Equality Division, Disability Policy Unit.

[75] Department of Health (DoH) (2012b) **Value for Money and Policy Review of Disability Services in Ireland**. Dublin: The Stationary Office.

[76] Kelly, C. (2015) **HRB Statistics Series 28 Annual report of the National Intellectual Disability Database committee 2014.** Dublin, Ireland: Health Research Board.

[77] McCarron, M., Swinburne, J., Burke, E., McGlinchey, E., Mulryan, N., Andrews, V., Foran, S. and McCallion, P. (2011) **Growing Older with an Intellectual Disability in Ireland 2011: First results from the Intellectual Disability Supplement of the Irish Longitudinal Study on Ageing**. Dublin, Ireland: School of Nursing and Midwifery, Trinity College Dublin.

[78] Thompson, R., Kerr, M., Glynn, M. and Linehan, C. (2014) Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives. **Seizure**, 23 (10), 856–863.

[79] Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., *et al.* (2014). **Mapping the National Disability Policy Landscape.** Dublin: School of Social Work and Social Policy, Trinity College.

[80] National Federation of Voluntary Bodies (NFVB) (2009) **Vision Statement for Intellectual Disability in Ireland for the 21st Century.** Galway, Ireland: National Federation of Voluntary Bodies Providing Services to People with Intellectual Disability.

and/or study outside the home for up to 15 hours a week. Carers who wish to leave work in order to provide care to a person(s) in need of full-time care, and who have paid sufficient social insurance contributions, may apply for Carer's Benefit for up to two years. Other financial supports, such as the annual Carer's Support Grant (formerly the Respite Care Grant) are available to eligible carers. While this grant was cut by 19% in the 2013 governmental budget, it was recently restored to €1,700 in the 2016 budget.

Family carers who receive a Carer's Allowance for a person with an intellectual disability can face particular challenges. This is especially the case when the person with intellectual disability turns 16 years of age. A child whose needs, owing to a disability, that are substantially in excess of the care and attention ordinarily required by a child, may receive Domiciliary Care Allowance (DCA) up until 16 years of age. This allowance is currently set at €309.50 a month. DCA is paid to an eligible child, not to their carer, which means that DCA is not counted as reckonable income in means-testing for Carer's Allowance, nor is it in determining a person's or a household's rental dues for social housing. Upon reaching 16 years of age, the person with intellectual disability who received the DCA may transfer to a Disability Allowance (DA). DA is paid to a person who is substantially restricted in undertaking work or training owing to a disability. The current DA rate is €188 weekly, though recipients must still satisfy a means test. At this point, there is also a review of the situation for both recipient and their carer, in receipt of a Carer's Allowance. The complexities inherent in this transition from one payment to another have been acknowledged by the DSP.[81] To reduce the associated burden experienced by families, the DSP have now committed to notifying households six months in advance of this transition from the DCA to DA, and providing an explanation of what this entails. This is in line with the recommendations from a recent review of the DCA.[81]

Despite improvements in the provision and administration of these financial supports, the transition for a family when a person with intellectual disability turns 16 years continues to present significant challenges. For example, there may be inadequate arrangements for transitioning from a mainstream to a special school, or to a post-secondary school. Furthermore, the long-term care systems in Ireland tends to focus on services for older people and younger children, with those between the ages of 16 and 65 experiencing significantly more difficulties with accessing appropriate services.

Several support organisations have been established to support parents and carers in Ireland. Family Carers Ireland (FCI) (formerly the Carers' Association and Caring for Carers) is a national voluntary organisation that offers supports to family carers who provide care in the home. Such supports include a Freephone Care Line, home respite services, advocacy, information, and training. Care Alliance Ireland is an organisation with a network of over 100 voluntary organisations that work with, and

[81] Report of the Review Group (2012) **Domiciliary Care Allowance Review.** Dublin: Report of the Review Group.

support family carers, and focus on raising awareness, as well as engaging in research and policy development. A number of other national organisations offer specialised information and support to families of a person with intellectual disability, such as the National Federation of Voluntary Bodies (NFVB), Inclusion Ireland, Down Syndrome Ireland, and Irish Autism Action.

Given the heterogeneous and changing nature of families where there is a person with intellectual disability, it can be difficult to develop appropriate caregiving supports. Each family caregiving situation is different with unique circumstances. As Chadwick and colleagues (2013) stated, 'policy makers, service providers and the wider community in Ireland and internationally should work more closely with families to address these needs to enable people with intellectual disabilities and their families to feel supported, empowered, included and afforded their basic human rights' (p. 130).[82]

1.4 Aim and Objectives

While family caregiving in the field of intellectual disability has received increased attention over the last number of years, [82,83,84,85,86] relatively little is still known about caregiving demands, family relationships, family supports, and compound caregiving prioritization. As stated by Rowbotham and colleagues (2011), 'if families are to be supported in their caring role, it is important that we develop a better understanding both of the demands they face, and of the mechanisms that allow them to continue their role' (p. 130).[87] To this end, the overarching aim of this study was to examine family carers' experiences of caring for a person with intellectual disability. The objectives of the study were to:

[82] Chadwick, D.D., Manna, H., Iriarte, E.G., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A. and Harrington, G. (2013) Family voices: Life for family carers of people with intellectual disabilities in Ireland. **Journal of Applied Research in Intellectual Disabilities,** 36, 119–132.

[83] Taggart, L., Truesdale-Kennedy, M., Ryan, A. and McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. **Journal of Intellectual Disabilities,** 16 (3), 217–234.

[84] O'Connell, T., O'Halloran, M., and Doody, O. (2013) Raising a child with disability and dealing with life events: A mother's journey. **Journal of Intellectual Disabilities,** 17 (4), 376–386.

[85] Ryan, A., Taggart, L., Truesdale-Kennedy, M. and Slevin, E. (2014). Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. **International Journal of Older People Nursing**, 9, 217–226.

[86] Daly, L., Sharek, D., DeVries, J., Griffiths, C., Sheerin, F., McBennett, P. and Higgins, A. (2015) The impact of four family support programmes for people with a disability in Ireland. **Journal of Intellectual Disabilities**, 19 (1), 34 – 50.

[87] Rowbotham, M., Cuskelly, M. and Carroll, A. (2011) Sustainable caregiving? Demands upon and resources of female carers of adults with intellectual disability. **Journal of Women and Aging,** 23, 129–148.

- Examine current support structures within families with a person with intellectual disability.
- Measure resilience among family carers of a person with intellectual disability.
- Identify factors that promote or hinder resilience within families with a person with intellectual disability.
- Examine social connectedness among family carers of a person with intellectual disability.
- Explore the 'compound carer's' experience of providing care for a person with intellectual disability, while also providing care for another person(s).

1.5 Study Design

This study adopted a mixed methods research design involving an anonymous postal survey of family carers of people with intellectual disability, followed by one-to-one, in-depth telephone interviews with compound carers.

1.6 Data Collection

The study was conducted in two phases. Phase 1 was facilitated by the DSP and consisted of an anonymous postal survey of 600 family carers who received a Carer's Allowance for the care of a person(s) with intellectual disability, aged 16 years and older. Data collection involved three separate mail-outs, which included an initial pre-notice letter informing respondents about the study and inviting them to participate in the survey, a questionnaire with a return stamped addressed envelope, and a reminder letter. This method was employed to ensure a high response rate and reflects best practice in survey research.[88] A total of 247 completed questionnaires were received, yielding a 41% response rate.

Phase 2 consisted of telephone interviews with compound carers. For the purposes of this study, a 'compound carer' referred to 'a person who provided full-time care to a person with intellectual disability and who also provided regular unpaid care to another person(s) requiring care, due to a long-term illness, disability, frailty or other impairment (e.g. to an elderly parent, a sibling with a physical disability etc.)'. The questionnaires that were distributed in Phase I were accompanied by a letter inviting respondents who met the criteria of the compound carer to take part in a one-to-one telephone interview about their experiences of caring for more than one person. Participants were asked to supply their contact details separate to their questionnaire responses using the second stamped addressed envelope provided. Interested respondents were contacted to arrange a convenient day and time for a

[88] Dillman, D., Smith, J.D. and Christian, L.M. (2009) **Internet, mail, and mixed-mode surveys: The tailored design method.** New Jersey: John Wiley & Sons.

telephone interview. A total of 14 eligible compound carers participated in a telephone interview.

Ethical approval was granted for both Phase 1 [Ref: LS-E-15-110-Lafferty] and Phase 2 [Ref: LS-15-67-Lafferty] by the UCD Human Research Ethics Committee [HREC] (see Appendix 1).

1.7 Data Analysis

Survey data collected in Phase I was coded, cleaned, and entered into a Statistical Package for Social Sciences (SPSS) version 20. Descriptive statistics were used to analyse the data. Frequencies, percentages, means and standard deviations are presented. Comparisons between groups were made using chi-square tests on categorical data and independent samples t-tests and analyses of variance (ANOVA) were performed using continuous variables. The Mann Whitney U test was used to look at associations between non-normally distributed data. Spearman's test of correlation was used to test for relationships between two variables with continuous data. Qualitative interview data from Phase 2 was analysed using content analysis and data analysis was supported by NVivo 9.0 software.

Chapter 2: Literature review

This chapter provides an overview of the national and international literature on family caregiving and intellectual and developmental disability, with a particular focus on the factors that enhance family resilience. The literature relating to the experience of the 'compound carer' is also outlined. Several scholarly databases were used to source relevant articles including PsycINFO, CINAHL, and EMBASE. Different combinations of variations of the following search terms were used: 'intellectual disability', 'family caregiving', 'compound caregiving' and 'resilience'.

2.1 Family Caregiving and Intellectual Disability

The majority of people with intellectual disability are cared for at home by family members.[89] While family caregiving for a person with intellectual disability can be a very enriching and a positive experience,[90,91] much of the published literature focuses on the demands and pressures often associated with caring for a person with intellectual disability.[92,93,94,95]

It has been well documented that parents and carers of children with intellectual and developmental disabilities experience higher levels of stress and parenting, than

[89] Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., *et al.* (2014). **Mapping the National Disability Policy Landscape.** Dublin: School of Social Work and Social Policy, Trinity College.

[90] Blacher, J. and Baker, B.L. (2007) Positive impact of intellectual disability on families. **American Journal on Mental Retardation**, 112 (5), 330–348.

[91] Green, S.E. (2007) "We're tired, not sad"; benefits and burdens of mothering a child with a disability. **Social Science and Medicine**, 64, 150–163.

[92] Blacher, J., Shapiro, J., Lopez, S. and Diaz, L. (1997) Depression in Latina mothers of children with mental retardation: a neglected concern. **American Journal on Mental Retardation**, 101, 483–496.

[93] Ben-Zur, H., Duvdevany, I. and Lury, L. (2005) Associations of social support and hardiness with mental health among mothers of adult children with intellectual disability. **Journal of Intellectual Disability Research**, 49, 54–62.

[94] Chou, Y., Pu, C., Lee, Y., Lin, L. and Kroger, T. (2009a) Effects of perceived stigmatisation on the quality of life among ageing family carers: A comparison of carers of adults with intellectual disability and carers of adults with mental illness. **Journal of Intellectual Disability Research**, 53, 654–664.

[95] Hill, C. and Rose, J. (2009) Parenting stress in mother of adults with an intellectual disability: Parental cognitions in relation to child characteristics and family support. **Journal of Intellectual Disability Research**, 53, 969–980.

parents of children without intellectual and developmental disabilities.[96,97,98] Lee (2013) conducted a literature review of studies that looked at the wellbeing of parents and, from a review of 28 scientific research papers, found that mothers of children with intellectual and developmental disability experience significantly higher levels of stress than mothers of typically developing children, with stress levels remaining high over time.

The literature also suggests that mothers of children with intellectual disability are much more likely to experience higher levels of anxiety and depression than mothers of children without an intellectual disability.[99,100,101] For example, a meta-analysis of findings from 18 studies showed that almost one third (29%) of mothers of children with developmental disabilities met or were above the clinical cut-off for high depressive symptoms, as compared to 19% of mothers of children without disabilities from a comparison group.[102]

The evidence also suggests that parents with children with intellectual disability are at increased risk of poor physical health.[103] An Irish study of parents of children with intellectual disability reported more physical health problems, such as sleep

[96] Hauser-Cram, P., Warfields, M.E., Shonkoff, J.P. and Krauss M.W. (2001) The development of children with disabilities and the adaptation of their parents: theoretical perspective and empirical evidence. **Monographs of the Society for Research in Child Development,** 66, 6–21.

[97] Baker, L.B., Blacher, J. and Olsson, M.B. (2005) Preschool children with and without developmental delay: Behaviour problems, parents' optimism and wellbeing. **Journal of Intellectual Disability Research**, 49, 575–590.

[98] Gerstein, E.D., Crnic, K.A, Blacher, J. and Baker, B.L. (2009) Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. **Journal of Intellectual Disability Research,** 53 (12), 981–997.

[99] Emerson, E. (2003) Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. **Journal of Intellectual Disability Research,** 47 (4-5), 385–399.

[100] Singer, G.H.S. (2006) Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. **American Journal on Mental Retardation**, 111 (3), 155–169.

[101] Lee, J. (2013) Maternal stress, well-being, and impaired sleep in mothers of children with developmental disabilities: A literature review. **Research in Developmental Disabilities**, 34 (11), 4255–4273.

[102] Singer, G.H.S. (2006) Meta-analysis of comparative studies of depression in mothers of children with and without developmental disabilities. **American Journal on Mental Retardation**, 111 (3), 155–169.

[103] Allik, H., Larsson, J.O., Smedje, H. (2006) Health-related quality of life in parents of school-age children with Asperger Syndrome or High-Functioning Autism. **Health and Quality of Life Outcomes**, 4, 1.

disturbances, headaches, gastrointestinal problems, and respiratory infection episodes, than parents of children without intellectual disability.[104]

Families of children with intellectual disability may also experience other problems, such as increased financial strain.[105] Secondary analysis of data from 9,726 mother-child dyads in the UK found that families supporting a child with intellectual disability were significantly more economically disadvantaged when compared with families supporting a child who did not have an intellectual disability.[106] Due to their caregiving responsibilities, families are further strained by parents' limited available time to engage in employment and within their community, which can lead to feelings of isolation.[107] Shearn and Todd (2000) reported that, in general, parents of children with intellectual disability experienced lower self-esteem and faced uncertainty about the future. Older parents, in particular, tend to be concerned and worried about the wellbeing of their son or daughter and the uncertainty of their future caregiving arrangements.[108,109] Adding to the stress, families of children with intellectual disabilities may experience negative attitudes from professionals and schools.[110]

Higher levels of stress experienced by parents of children with intellectual disability may be attributable to a range of factors including the type of disability or disorder,[111]

[104] Gallagher, S. and Whiteley, J. (2012) The association between stress and physical health in parents caring for children with intellectual disabilities is moderated by children's challenging behaviours. **Journal of Health Psychology**, 18 (9), 1220–1231.

[105] Gunn, P. and Berry, P. (1987) Some financial costs of caring for children with Down syndrome at home. **Australia and New Zealand Journal of Developmental Disabilities**, 13, 187–193.

[106] Emerson, E. (2003) Mothers of children and adolescents with intellectual disability: social and economic situation, mental health status, and the self-assessed social and psychological impact of the child's difficulties. **Journal of Intellectual Disability Research,** 47 (4-5), 385–399.

[107] Shearn, J., and Todd, S. (2000) Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. **Journal of Applied Research in Intellectual Disabilities**, 13, 109–131.

[108] Taggart, L., Truesdale-Kennedy, M., Ryan, A. and McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. **Journal of Intellectual Disabilities,** 16 (3), 217–234.

[109] Chadwick, D.D., Manna, H., Iriarte, E.G., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A. and Harrington, G. (2013) Family voices: Life for family carers of people with intellectual disabilities in Ireland. **Journal of Applied Research in Intellectual Disabilities,** 36, 119–132.

[110] Blacher, J., and Hatton, C. (2009) Families in context: Influences on coping and adaptation. In S.L. Odom, R.H. Horner, M.E. Snell, and J. Blacher (Eds.), Handbook of developmental disabilities (pp. 531– 551). New York, NY: Guilford Press.

[111] Gupta, V. B. (2007) Comparison of parenting stress in different developmental disabilities. **Journal of Developmental and Physical Disabilities**, 19, 417–425.

challenging behaviours,[112] or the severity of the disability.[113] Ekas and Whitman (2010) undertook a study with 119 American mothers of children and young adults with Autism Spectrum Disorder (ASD) and found that the greater the severity of symptoms, the greater the prevalence of depression among mothers, as well as there being evidence of poorer psychological wellbeing and life satisfaction.

Mental health problems experienced by the person with intellectual disability may also be a contributing factor to parental stress levels.[114] A recent Irish study of 75 family carers of adults with intellectual disability living at home examined the impact of caring for an adult with intellectual disability and psychopathological comorbidities. The study reported that carers of people with intellectual disability, who also had psychiatric comorbidities, had significantly higher levels of stress and psychological distress than carers of adults who only had intellectual disabilities.[115] The presence of other health problems often associated with intellectual disabilities, such as epilepsy, may also increase carer burden levels.[116]

Prolonged carer stress can have other significant consequences for families and the person with intellectual disability, leading to an increased risk of marital problems and family dysfunction.[117,118,119] Studies have shown that families' experience of stressors is also dependent on life stages and childhood development.[83]

[112] Allik, H., Larsson, J.O., Smedje, H. (2006) Health-related quality of life in parents of school-age children with Asperger Syndrome or High-Functioning Autism. **Health and Quality of Life Outcomes**, 4, 1.

[113] Hoare P., Harris M., Jackson P. and Kerley S. (1998) A community survey of children with severe intellectual disability and their families: psychological adjustment, carer distress and the effect of respite care. **Journal of Intellectual Disability Research**, 42, 218–227.

[114] Faust, H. and Scior, K. (2008) Mental health problems in young people with intellectual disabilities: The impact on parents. **Journal of Applied Research in Intellectual Disabilities***,* 21, 414–424.

[115] Dawson, F., Shanahan, S., Fitzsimons, E., O'Malley, G., Mac Giollabhui, N., and Bramham J. (2016) The impact of caring for an adult with intellectual disability and psychiatric comorbidity on care stress and psychological distress. **Journal of Intellectual Disability Research**, 60 (6), 553–563.

[116] Thompson, R., Kerr, M., Glynn, M. and Linehan, C. (2014) Caring for a family member with intellectual disability and epilepsy: Practical, social and emotional perspectives. **Seizure***,* 23 (10), 856–863.

[117] Al-Krenawi, A., Graham, J. R., and Al Gharaibeh, F. (2011) The impact of intellectual disability, caregiver burden, family functioning, marital quality, and sense of coherence. **Disability and Society**, 26, 139–150.

[118] Hatton, C., Emerson, E., Graham, H., Blacher, J. and Llewellyn, G. (2010). Changes in family composition and marital status in families with a young child with cognitive delay. **Journal of Applied Research in Intellectual Disabilities**, 23, 14–26.

[119] Gerstein, E.D., Crnic, K.A, Blacher, J. and Baker, B.L. (2009) Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. **Journal of Intellectual Disability Research,** 53 (12), 981–997.

2.2 Resilience and Families of a Person with Intellectual Disability

All families are heterogeneous and vary in their functioning, structures, personalities and propensity for adaptation.[120] Therefore, despite the challenges associated with caring for a child with intellectual and developmental disabilities, many families adapt successfully, and even thrive, following the child's birth or diagnosis.[121,122]

The process which enables one to adapt, manage, and negotiate such strains and adversities is often referred to as 'resilience'.[123] According to resilience theory, resilience is determined by balancing risk and protective factors in the face of adversity.[124] While there is no universally accepted definition of resilience, resilience within families can be defined as 'the characteristics, dimensions, and properties, which help families to be resistant to disruption in the face of change and adaptive in the face of a crisis situation' (p. 247).[125]

A number of studies have reported that resilience levels among parents of children with intellectual disability are lower than that of the general population.[126,127,128] The more resilient families are, the better able they are to manage adversities associated with their caring circumstances.[129] A multitude of factors can influence a family's ability to provide care including social, psychosocial, financial, and physical factors

[120] Chadwick, D.D., Finlay, F., García Iriarte, E., Greene, S., Harrington, J., Lawlor, A., Mannan, H., McConkey, R., O'Brien, P., Spain, J. and Turner, A. (2010) **Family Voices: Life in Ireland for families of people with intellectual disabilities.** Dublin: National Institute for Intellectual Disability, Trinity College Dublin.

[121] Hastings, R.P. and Taunt, H.M. (2002) Positive perceptions of families of children with developmental disabilities. **American Journal on Mental Retardation**, 107, 116–127.

[122] Bayat, M. (2007) Evidence of resilience in families of children with autism. **Journal of Intellectual Disability Research**, 51, 702–714.

[123] Windle, G. (2011) What is resilience? **Reviews in Clinical Gerontology**, 21, 152– 169.

[124] Luthar, S., Cicchetti, D. and Becker, B. (2000) The construct of resilience: A critical evaluation and guidelines for future work. **Child Development**, 71, 543–562.

[125] McCubbin, H. I., and McCubbin, M.A. (1988) Typologies of resilient families: emerging roles of social class and ethnicity. **Family Relations**, 37, 247–254.

[126] Baxter, C., Cummins, R.A. and Yiolitis, L. (2000) Parental stress attributed to family members with and without disability: A longitudinal study. **Journal of Intellectual and Developmental Disability**, 25, 105–118.

[127] Baker, L.B., Blacher, J. and Olsson, M.B. (2005) Preschool children with and without developmental delay: Behaviour problems, parents' optimism and wellbeing. **Journal of Intellectual Disability Research**, 49, 575–590.

[128] Wong, P.K.S. and Lam, T.L. (2015) Enhancing the resilience of parents of adults with intellectual disabilities through volunteering: An exploratory study. **Journal of Policy and Practice in Intellectual Disabilities,** 12 (1), 20–26.

[129] Bekhet, A.K., Johnson, N.L. and Zauszniewski, J.A. (2012) Resilience in family members of persons with autism spectrum disorder: a review of the literature. **Issues in Mental Health Nursing**, 33 (10), 650–656.

that are specific to each family caregiving context.[130] Enhancing resilience within families can be possible through the identification of risk factors.

2.3 Factors Associated with Resilience in Families with a Person with Intellectual Disability

Studies have highlighted a range of strategies adopted by families and have revealed that carers apply a variety of problem-solving, cognitive-coping, and stress-reducing approaches in order to adapt in adverse situations and overcome the challenges associated with their caregiving roles.[131] The capacity to adopt these approaches can be influenced by different individual characteristics,[131,132] social factors,[133,134,135,136,137] and environmental contexts.[138,139,140] An examination of the interrelatedness of these

[130] Windle, G. and Bennett, K.M. (2012) **Caring relationships: How to promote resilience in challenging times.** In M. Ungar, The social ecology of resilience: A handbook of resilience and practice (219–231). London: Springer.

[131] Grant, G., and Whittell, B. (2000) Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the lifespan. **Journal of Applied Research in Intellectual Disabilities**, 13 (4), 256–75.

[132] Llewellyn, G., McConnell, D., Gething, L., Cant, R. and Kendig, H. (2010) Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. **Research in Developmental Disabilities**, 31 (6), 1176-1186.

[133] Herrman, H., Stewart, D., Diaz-Granados, N., Berger, E., Jackson, B. and Yuen T. (2011) What is resilience? **Canadian Journal of Psychiatry**, 56(5), 258–265.

[134] Gerstein, E.D., Crnic, K.A, Blacher, J. and Baker, B.L. (2009) Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. **Journal of Intellectual Disability Research,** 53 (12), 981–997.

[135] Chadwick, D.D., Manna, H., Iriarte, E.G., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A. and Harrington, G. (2013) Family voices: Life for family carers of people with intellectual disabilities in Ireland. **Journal of Applied Research in Intellectual Disabilities,** 36, 119–132.

[136] Friborg, O., Hjemdal, O., Rosenvinge, J.H. and Martinussen, M. (2003) A new rating scale for adult resilience: What are the central protective resources behind healthy adjustment? **International Journal of Methods in Psychiatric Research,** 12 (2), 65–76.

[137] Grant, G., and Ramcharan, P. (2001) Views and experiences of people with intellectual disabilities and their families: (2) The Family Perspective. **Journal of Applied Research in Intellectual Disabilities**, 14 (4), 364–80.

[138] Grant, G., Ramcharan, P. and Flynn, M. (2007) Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. **Journal of Applied Research in Intellectual***,* 20 (6), 563–575.

[139] Ouellette-Kuntz, H., Blinkhorn, A., Rouette, J., Blinkhorn, M., Lunsky, Y. and Weiss, J. (2014) Family resilience: An important indicator when planning services for adults with intellectual and developmental disabilities. **Journal on Developmental Disabilities**, 20 (2), 55–66.

[140] Peer, J. W. and Hillman, S.B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (2), 92–98.

factors provides useful insight into carers' experiences of developing, maintaining, and enhancing resilience.

2.3.1 Individual Factors Associated with Family Resilience

Individual characteristics associated with resilience include age, gender, life stage, caring workload, and the dependency levels of the care-recipient, as well as concepts of personal beliefs, acceptance, perceptions of self, and self-efficacy.[141,142,143,144] Maintaining a sense of control, and having valued identities have been found to be important elements in enabling carers to maintain resilience and to positively adapt to the challenges associated with caregiving.[145,146,147] Peer and Hillman (2014) undertook a comprehensive review of the literature and found that coping style and optimism were key protective factors associated with resilient processes in parents of children with intellectual disability. Similarly, a study of 214 mothers of pre-school aged children with intellectual disabilities found that those who were more optimistic had higher levels of wellbeing than mothers who were less optimistic.[148] A study of 126 parents of children with Down syndrome in Korea also found that good parental mental health was strongly related to a family's resilience.[149] In addition, higher levels of resilience among families of children with autism have been shown to be linked with higher levels of perceived health.[150] Other studies have reported that

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[141] Bekhet, A.K., Johnson, N.L. and Zauszniewski, J.A. (2012) Resilience in family members of persons with autism spectrum disorder: a review of the literature. **Issues in Mental Health Nursing**, 33 (10), 650–656.

[142] Grant, G., and Whittell, B. (2000) Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the lifespan. **Journal of Applied Research in Intellectual Disabilities**, 13 (4), 256–75.

[143] Llewellyn, G., McConnell, D., Gething, L., Cant, R. and Kendig, H. (2010) Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. **Research in Developmental Disabilities**, 31 (6), 1176-1186.

[144] Bayat, M. (2007) Evidence of resilience in families of children with autism. **Journal of Intellectual Disability Research**, 51, 702–714.

[145] Grant, G., Ramcharan, P. and Flynn, M. (2007) Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. **Journal of Applied Research in Intellectual**, 20 (6), 563–575.

[146] Grant, G., Ramcharan, P. and Goward P. (2003) Resilience, family care, and people with intellectual disabilities. **International Review of Research in Mental Retardation**, 26, 135–173.

[147] Windle, G. (2011) What is resilience? **Reviews in Clinical Gerontology**, 21, 152– 169.

[148] Baker, L.B., Blacher, J. and Olsson, M.B. (2005) Preschool children with and without developmental delay: Behaviour problems, parents' optimism and wellbeing. **Journal of Intellectual Disability Research**, 49, 575–590.

[149] Choi, E.K. and Yoo, I.Y. (2015) Resilience in families of children with Down syndrome in Korea. **International Journal of Nursing Practice**, 21, 532–541.

[150] Ruiz-Robledillo, N., De Andrés-García, S., Pérez-Blasco, J., González-Bono, E. and Moya-Albiol, L. (2014) Highly resilient coping entails better perceived health, high social support and low morning cortisol levels in parents of children with autism spectrum disorder. **Research in Developmental Disabilities**, 35 (3), 686–695.

rationalising the day-to-day struggles and embracing the perplexity of caring circumstances,[151] positive reappraisal,[152] as well as having positive attitudes towards new experiences were all strategies that related to carers' coping abilities.[153]

2.3.2 Social Factors Associated with Family Resilience

Social factors associated with family resilience include family cohesion, close family relationships, social competence, and social support.[154,155,156] Having strong supportive relationships within families caring for a person with intellectual disability is considered to be a protective factor associated with resilience.[155,157,158] Bayat (2007) undertook a survey of 175 parents of children with autism and found that, even despite extraordinary challenges facing the families, there was evidence of resilience. The two factors identified that were particularly necessary for families to be resilient included their ability to pool resources together and to stay connected. A collective commitment to manage familial responsibilities and support family functions of caregiving, childrearing, and communication has been shown to contribute overall to positive family functioning.[156] Choi and Yoo (2015) found that family cohesiveness and communication skills were factors that were strongly related to resilience in families of children with Down syndrome. Their findings are consistent with a South African study of family carers of children with developmental disabilities, which reported that the most significant predictor of family adaptation

[151] Grant, G., and Whittell, B. (2000) Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the lifespan. **Journal of Applied Research in Intellectual Disabilities**, 13 (4), 256–75.

[152] Paster, A., Brandwein, D. and Walsh, J. (2009) A comparison of coping strategies used by parents of children with disabilities and parents of children without disabilities. **Research in Developmental Disabilities,** 30(6), 1337–1342.

[153] Greeff, A.P. and Nolting, C. (2013) Resilience in families of children with developmental disabilities. **Family Systems and Health,** 31 (4), 396-405.

[154] Grant, G., Ramcharan, P. and Flynn, M. (2007) Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. **Journal of Applied Research in Intellectual**, 20 (6), 563–575.

[155] Gerstein, E.D., Crnic, K.A, Blacher, J. and Baker, B.L. (2009) Resilience and the course of daily parenting stress in families of young children with intellectual disabilities. **Journal of Intellectual Disability Research,** 53 (12), 981–997.

[156] Bekhet, A.K., Johnson, N.L. and Zauszniewski, J.A. (2012) Resilience in family members of persons with autism spectrum disorder: a review of the literature. **Issues in Mental Health Nursing**, 33 (10), 650–656.

[157] Walsh, F. (2003) Family resilience: a framework for clinical practice. **Family Process**, 42 (1), 1-18.

[158] Peer, J. W. and Hillman, S.B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (2), 92–98.

was the quality of family patterns of communication, as well as a shared commitment to the family unit.[159]

Peer and Hillman (2014) stated that social support networks play a critical role to creating cohesion within families where there is a person with intellectual disability. Maintaining stable social networks can provide emotional and informational support to families, offering important resources for sustaining them in their caregiving roles. For example, a small qualitative study of parents of children with disabilities found that those who were strongly connected to faith communities displayed more resilient attitudes and behaviours.[160] A study with older parental carers of adults with intellectual disabilities found better health outcomes were associated with having an intimate partner, as well as having larger and close support networks of family, friends, and neighbours.[161] Other studies have also reported that spouses and partners are greater sources of social support; more than social clubs or groups.[162] However, carers may struggle to maintain social support structures as they age. A study that looked at the importance of social supports in older family carers of an individual with intellectual and developmental disabilities revealed that the internet can be a useful medium for social engagement.[163]

Some studies claim that it is not the number of social supports, but rather the perceived quality of social supports, that relate positively to resilience in mothers of children with intellectual disability.[164] A study conducted in the U.S. of 97 mothers of children aged 2 to 18 years with pervasive developmental disorders, reported that mothers who were more satisfied with their social supports had lower levels of psychological distress.[165] Similarly, a study of 143 mothers of children with ASD by

[159] Greeff, A.P. and Nolting, C. (2013) Resilience in families of children with developmental disabilities. **Family Systems and Health,** 31 (4), 396-405.

[160] Richardson, E.W. and Stoneman, Z (2015). The road to membership: The role of resilience in seeking and maintaining membership in a faith community for families of children with disabilities. **Journal of Disability and Religion**, 19 (4), 312–339.

[161] Llewellyn, G., McConnell, D., Gething, L., Cant, R. and Kendig, H. (2010) Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. **Research in Developmental Disabilities**, 31 (6), 1176-1186.

[162] Hall, H.R. and Graff, J.C. (2011) The relationships among adaptive behaviours of children with autism, family support, parenting stress, and coping. **Issues in Comprehensive Pediatric Nursing**, 34 (1), 4–25.

[163] Perkins, E.A. and LaMartin, K.M. (2012) The internet as social support for older carers of adults with intellectual disabilities. **Journal of Policy and Practice in Intellectual Disabilities,** 9 (1), 53–62.

[164] Bayrakli, H. and Kaner, S. (2012) Investigating the factors affecting resiliency in mothers of children with and without intellectual disability. **Educational Sciences: Theory and Practice**, 12 (2), 936–943.

[165] Tobing, L.E. and Glenwick, D.S. (2006) Predictors and moderators of psychological distress in mothers of children with pervasive development disorders. **Journal of Family Social Work**, 10 (4), 1–22.

Carter and colleagues (2009), found that levels of perceived availability of social support were negatively correlated with levels of depression.

Research with older caregivers has reported that those working and volunteering outside the home had better self-rated health and were better able to maintain informal social connections.[166] However, those who take on caregiving responsibilities are likely to decrease their number of working hours, or even leave the workforce altogether.[167] The same study also showed that employment retention increased when carers had access to flexible work hours, unpaid family leave, and paid days off.[167]

2.3.3 Environmental Factors Associated with Family Resilience

Environmental factors associated with resilient processes in caring families include the availability of appropriate community resources, access to formal supports and services, as well as having facilitative policies.[168,169,170] Ungar (2011) argued that resilience has less to do with individual or intrinsic factors, and more to do with the availability and accessibility of culturally relevant resources. Consistent with this assertion, are findings from a Canadian study of 538 parents who participated in a Family Life Survey.[171] The study reported that in families raising children with disabilities and behavioural problems, resilience was more likely to be related to high levels of social supports and low financial hardship, than to individual or family factors.

Some families can feel completely overwhelmed by the challenges often associated with accessing and navigating services, which can often be fragmented, inflexible, and under-resourced.[172] A US study reported that siblings of people with intellectual disability who had greater access to services experienced greater well-being and

[166] Rozario, P.A., Morrow-Howell, N. and Hinterlong, J.E. (2004) Role enhancement or role strain. Assessing the impact of multiple productive roles on older caregiver well-being. **Research in Aging**, 26 (4), 413–418.

[167] Pavalko, E.K. and Henderson, K.A. (2006) Combining care work and paid work: Do workplace policies make a difference? **Research on Aging,** 28 (3), 359–374.

[168] Ouellette-Kuntz, H., Blinkhorn, A., Rouette, J., Blinkhorn, M., Lunsky, Y. and Weiss, J. (2014) Family resilience: An important indicator when planning services for adults with intellectual and developmental disabilities. **Journal on Developmental Disabilities**, 20 (2), 55–66.

[169] Pottie, C.G. and Ingram, K.M. (2008) Daily stress, coping, and well-being in parents of children with autism: A multilevel modelling approach. **Journal of Family Psychology***,* 22 (6), 855–864.

[170] McConkey R. (2005) Fair shares? Supporting families caring for adult persons with intellectual disabilities. **Journal of Intellectual Disability Research**, 49 (8), 600-612.

[171] McConnell, D., Savage, A. and Breitkreuz R. (2014) Resilience in families raising children with disabilities and behaviours problems. **Research in Developmental Disabilities**, 35, 833–848.

[172] Browne, D.T., Rokeach, A., Wiener, J., Hoch, J.S., Meunier, J.C. and Thurston, S. (2013) Examining the family-level and economic impact of complex child disabilities as a function of child hyperactivity and service integration. **Journal of Developmental and Physical Disabilities**, 25 (2), 181–201.

were better able to support their brothers and sisters with intellectual disability.[173] Maintaining good relationships with services can be also linked to family resilience. A study with parents of children with disabilities found that being able to communicate openly and discuss concerns, not only with other family members, but also with professionals, promoted resilience within the family.[174] Formal supports such as help from professionals and support groups can often provide confidence and reassurance to parents as they care for their child with intellectual disability.[175]

McConnell and Savage (2015) highlighted the socio-ecological constraints on families and advocated for socio-political action and policy reform aimed at creating change and offering interventions that help families 'sustain meaningful daily routine'. Their argument placed less of a focus on helping families to cope and more attention on providing the same opportunities to families of children with intellectual disabilities as to those families of children without intellectual disability.

2.4 The Compound Carer

As life expectancies increase, both for the general population and for people with intellectual disability,[176] the role of carers is being extended to provide care for more than one person, and perhaps even across more than one generation.[177] In this regard, a 'compound carer' can be defined as a person with multiple caregiving roles,[178] and may be one of the most demanding life situations that a caregiver will contend with. The responsibility of having an additional care-recipient can be placed on a mother, father, spouse, sibling, or other family relative, with periods of compound caregiving occurring at different times in a person's life. Notwithstanding, there is still a limited amount of information in the literature that formally investigates this extension of the caregiving role for carers and parents of a person with intellectual disability.

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[173] Holl, E. and Morano, C.L. (2014) Supporting the next generation of caregivers: Service use and needs of adult siblings of individuals with intellectual disability. **Inclusion**, 2 (1), 2–6.

[174] Heiman, T. (2002). Parents of children with disabilities: Resilience, coping, and future expectations. **Journal of Developmental and Physical Disabilities**, 14, 159–171.

[175] Peer, J. W. and Hillman, S.B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (2), 92–98.

[176] Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., *et al.* (2014). **Mapping the National Disability Policy Landscape.** Dublin: School of Social Work and Social Policy, Trinity College.

[177] Windle, G. and Bennett, K.M. (2012) **Caring relationships: How to promote resilience in challenging times.** In M. Ungar, The social ecology of resilience: A handbook of resilience and practice (219–231). London: Springer.

[178] Perkins, E.A., and Haley, W.E. (2010) Compound caregiving: When lifelong caregivers undertake additional caregiving roles. **Rehabilitation Psychology**, 55 (4), 409–417.

2.4.1 Prevalence of Compound Carers

Parents of a child with intellectual disability may find themselves becoming a compound carer, assuming the caregiving role for a second family member.[179] Perkins and Haley (2010) conducted interviews with 91 carers living with an adult child with intellectual disability and found that over a third of participants (37%) were currently compound carers; this means that in addition to their child, they were also providing care to a mother, father, or spouse. This proportion of carers rose to two thirds when those who had previously occupied compound caring roles were included.[179] Study participants indicated that they provided an average of 12 hours of additional care per week to another person. The median duration of compound caregiving was three years.[179]

2.4.2 Sandwich Carers

Such compound caregiving roles are inclusive of the 'sandwich carer'. This means that as people are now living longer, there is an increase in the number of carers who find themselves 'sandwiched' between two generations. Sandwich carers provide care across generations, usually to an elderly parent or parent-in-law, while simultaneously providing care to their own children. Many sandwich carers find themselves with competing caregiving demands and having to prioritise the care of their children over their elderly parents.[180] Some studies have shown that sandwich carers experience a lower quality of life than non-sandwich carers.[181] This is particularly relevant for parents of children with intellectual disability who, since their children often remain living at home longer than their siblings, remain an important source of practical and emotional care and support for their son or daughter into their adult lives.[182] Some parental carers find themselves compound caregiving for a child with a disability in addition to a second or even third child with disability or other complex needs.

[179] Perkins, E.A., and Haley, W.E. (2010) Compound caregiving: When lifelong caregivers undertake additional caregiving roles. **Rehabilitation Psychology**, 55 (4), 409–417.

[180] Kwok, H. (2006) The son also acts as major caregiver to elderly parents: A study of the sandwich generation in Hong Kong. **Current Sociology,** 54 (2), 257–272.

[181] Rubin, R.M. and White-Means, S.I. (2009) Informal caregiving: Dilemmas of sandwiched caregivers. **Journal of Family and Economic Issues**, 30 (3), 252–267.

[182] Barron, S., McConkey, R. and Mulvany, F. (2006) Family carers of adult persons with intellectual disabilities on the Island of Ireland. **Journal of Policy and Practice in Intellectual Disabilities,** 3 (2), 87–94.

2.4.3 Sibling Carers

Compound caregiving does not occur just for parents.[183] Siblings, for instance, may end up assuming caregiving responsibilities as a result of changing family circumstances. For example, the loss of an elderly parent may lead to the transfer and accommodation of new caring roles and family support structures.[184] Studies have shown that often siblings of a disabled brother or sister are expected to take over the caring responsibilities when parents are no longer able to provide care.[185,186]

2.4.4 The Future of Compound Caregiving

Since the majority of primary carers of people with intellectual disability are parents or siblings,[187,188] vital shifts in relationships and support networks can occur when individuals take on carer responsibilities for a family member who may have previously had a primary caring or personal support role.[189,190,191] Regardless, these compound caring roles and responsibilities are likely to become increasingly common among caregivers of adults with intellectual disabilities.[192]

Given the unique dynamics and changing circumstances of families caring for people with intellectual disability, there can be a variety of reasons as to why carers may come into any combination of these caring situations. Similarly, there will be variations in the way carers manage convergent demands and adapt to the provision

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[183] Perkins, E.A. (2010) The compound caregiver: A case study of multiple caregiving roles. **Clinical Gerontologist**, 33, 248–254.

[184] Tebes, J.K. and Irish, J.T. (2000) Promoting resilience among children of sandwiched generation caregiving women through caregiver mutual help. **Journal of Prevention and Intervention in the Community**, 20 (1-2), 139–158.

[185] Chou Y, Lee Y, Lin L, Kröger, L. and Chang A (2009b) Older and younger family caregivers of adults with intellectual disability: factors associated with future plans. **Intellectual and Developmental Disabilities**, 47 (4), 282–294.

[186] Dew, A., Llewellyn, G., and Balandin, S. (2004) Post-parental care: A new generation of sibling-carers. **Journal of Intellectual and Developmental Disability**, 29, 176–179.

[187] Grant, G., and Whittell, B. (2000) Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the lifespan. **Journal of Applied Research in Intellectual Disabilities**, 13 (4), 256–75.

[188] Lunsky, Y., Tint, A., Robinson, S., Gordeyko, M. and Ouellette-Kuntz, H. (2014) System-wide information about family carers of adults with intellectual/developmental disabilities—a scoping review of the literature. **Journal of Policy and Practice in Intellectual Disabilities,** 11 (1), 8-18.

[189] Perkins, E.A. (2010) The compound caregiver: A case study of multiple caregiving roles. **Clinical Gerontologist**, 33, 248–254.

[190] Green, S.E. (2013) Convergent caregiving: Exploring eldercare in families of children with disabilities. **Journal of Loss and Trauma**, 18 (4), 289–305.

[191] Steiner, A. (2015) The lived experiences of sandwich generation women and their health behaviours. **Theses and Dissertations (Comprehensive).** Paper 1722.

[192] Perkins, E.A., and Haley, W.E. (2010) Compound caregiving: When lifelong caregivers undertake additional caregiving roles. **Rehabilitation Psychology**, 55 (4), 409–417.

of care for more than one person. As such, it is important to look at the impact of positive adaptation, cognitive coping, and management processes on primary care-recipients, other care-recipients, as well as carers themselves.[193]

2.5 Conclusion

Overall, resilience is more than just coping. It is a process of thriving, brought about through the acquisition of new skills, personal development, confidence, improved social relationships, and professional supports.[194] As the population ages and family structures change, the nature of caregiving for families with a person with an intellectual disability is likely to transform and a greater number of parents, carers, spouses, and siblings will likely find themselves becoming a compound carer. A better understanding and recognition of the unique caring circumstances and structures of families caring for persons with intellectual disability can be used to identify risk factors, promote protective factors, enhance positive adaptation, and manage caring processes. A focus on maximising resilience can help to ensure that family caregiving can be sustained and continues to be a valuable resource.

[193] Tebes, J.K. and Irish, J.T. (2000) Promoting resilience among children of sandwiched generation caregiving women through caregiver mutual help. **Journal of Prevention and Intervention in the Community**, 20 (1-2), 139–158.

[194] Grant, G., Ramcharan, P. and Flynn, M. (2007) Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. **Journal of Applied Research in Intellectual**, 20 (6), 563–575.

Chapter 3: Findings Phase 1- Survey of Family Carers

This chapter presents findings from Phase 1 of the study. The overall aim of this phase was to examine family carers' experiences of caring for a person with intellectual disability. A total of 247 family carers, in receipt of a Carer's Allowance for the care they provided to a relative aged 16 years and older with an intellectual disability and/or autism, participated in an anonymous postal survey. The questionnaire data were coded, entered, and analysed using IBM SPSS Statistics 20. Both descriptive and inferential statistics were used in the data analysis. Descriptive statistics (frequencies, percentages, means and standard deviations) were used to summary the data. The T-test, the Mann Whitney U and Pearson's chi-square test were used to make inferences about the data. The survey findings are presented in relation to the profile of carers, caregiving activities, the profile of care-recipients, carers' health and wellbeing, social connectedness, caregiving supports, and carer resilience.

3.1 Profile of Carers

Participants were asked to provide demographic information about themselves. Table 3.1 summarises the profile of the carers who participated in the survey. Carers' age ranged from 24 to 86 years, with a mean age of 52 years (SD = 9.8). Just 9.3% of carers (22/237) were aged 65 years and older. The vast majority of carers were female (81.1%; 198/244) and indicated that they were Irish (93.5%; 229/245).

Respondents were asked to report their marital status and the findings show that the majority of carers (57.8%; 141/244) were married or in a civil partnership; approximately 23.0% (56/244) reported that they were separated, divorced, or widowed, and 13.1% (32/244) indicated that they were single or never married.

Almost two thirds of carers (65.3%; 156/239) reported that they had secondary school, primary school, or no formal education. Just over a fifth of carers (21%; 50/239) indicated that they had attained a third level education qualification.

The majority of respondents (53.7%; 113/244) indicated that they resided in an urban area with the vast majority (92.6%; 226/244) reporting that they lived with the person with intellectual disability to whom they provided care and for whom they received a Carer's Allowance.

Table 3.1 Carers' Profile

Characteristic	% (n)
Gender	
Females	81.1 (198)
Males	18.9 (46)
Ethnic/cultural background	
Irish	93.5 (229)
Other European	4.5 (11)
Non-European	2.0 (5)
Marital status	
Single (Never married)	13.1 (32)
Married/Civil partnership	57.8 (141)
Living with a partner	6.1 (15)
Separated/Divorced	15.6 (38)
Widowed	7.4 (18)
Highest educational qualification	
No formal education/primary education	15.5 (37)
Junior Certificate/Intermediate Certificate (or equivalent)	31.0 (74)
Leaving Certificate (or equivalent)	18.8 (45)
Vocational/Technical qualification (e.g. FETAC Level 5)	13.8 (33)
Third-level Non-Degree (e.g. University Certificate, Diploma)	15.1 (36)
Third-level Degree or Higher (e.g. Bachelor's, Master's, Doctoral Degree)	5.9 (14)
Location	
Rural (a population of less than 1,500 people)	46.3 (113)
Urban (a population of more than 1,500 people)	53.7 (131)
Living arrangements	
Co-residing with the care-recipient	92.6 (226)
Not residing with the care-recipient	7.4 (18)

As illustrated by Figure 3.1, over two thirds of carers (69.9%; 165/236) indicated that they were a mother to a person with intellectual disability, and 13.6% (32/236) of carers reported that they were a father to the care-recipient with intellectual disability. Smaller proportions of carers identified themselves as either a sister 7.2% (17/236) or a brother (3.4%; 8/236) to their relative with intellectual disability and 5.5% (13/236) reported that they were an 'other relative' such as a niece, nephew, cousin, etc. Just one respondent (0.4%; 1/236) indicated that they were a non-relative and were a friend to the person with intellectual disability for whom they received a Carer's Allowance.

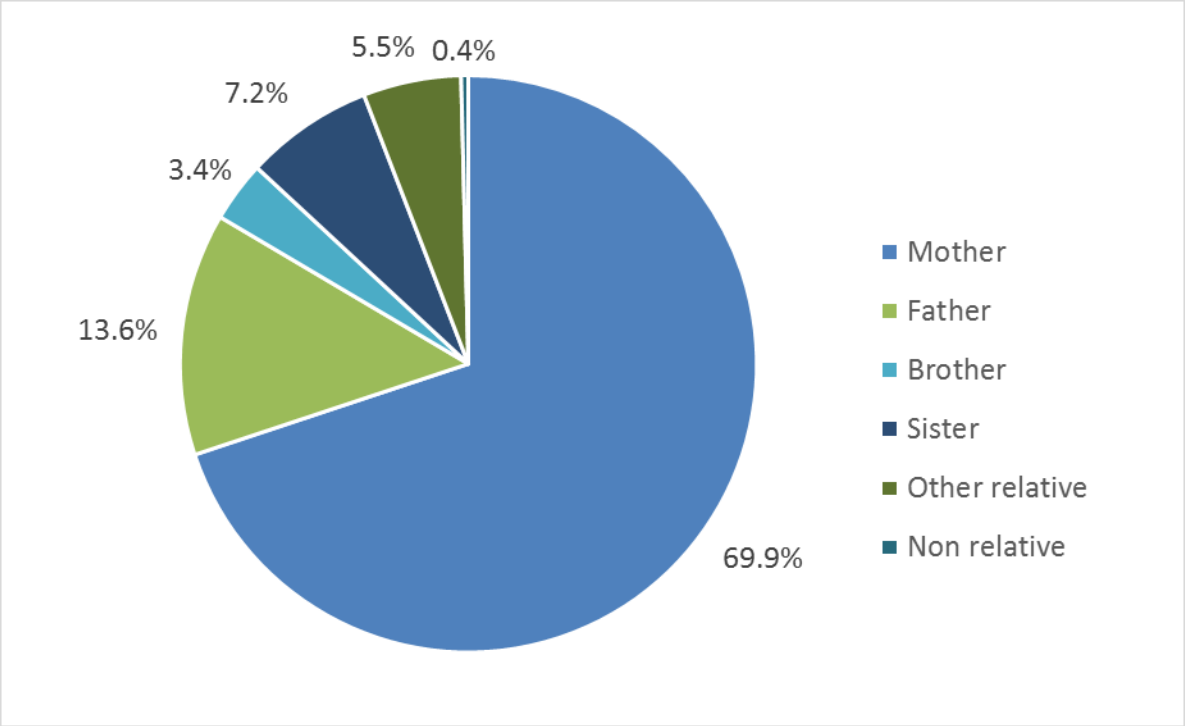

Figure 3.1 Carer Relationship to Person with Intellectual Disability

3.2 Caregiving Activities

Respondents were asked a number of questions relating to the care they provided to their relative with intellectual disability. Findings show the range of time for which carers were providing care was between less than 1 year and 47 years, and for an average of 15 years (SD = 8.9). Almost three quarters of respondents (72.2%; 17/237) indicated that they provided care for more than 100 hours a week, suggesting that they provided care for 24 hours a day, for 7 days a week (Figure 3.2). Approximately 14.8% (35/237) provided care for between 80 to 100 hours a week, and 6.3% (15/237) indicated that they provided care for between 50 and 79 hours a week. Smaller proportions of carers (3.4%; 8/237) indicated that they provided care for up to 49 hours a week.

The majority of respondents (69.4%; 168/242) indicated that they were in receipt of a full-rate Carer's Allowance; a payment paid by the DSP to carers who provide care to a person in need of full-time care (Table 3.2). Over a quarter of respondents (28.1%; 68/242) reported that they received a half-rate Carer's Allowance, a payment for carers who are also in receipt of another social welfare payment, such as a one-parent family payment. A total of 2.5% of respondents (6/242) responded that they were unsure which type of Carer's Allowance they received.

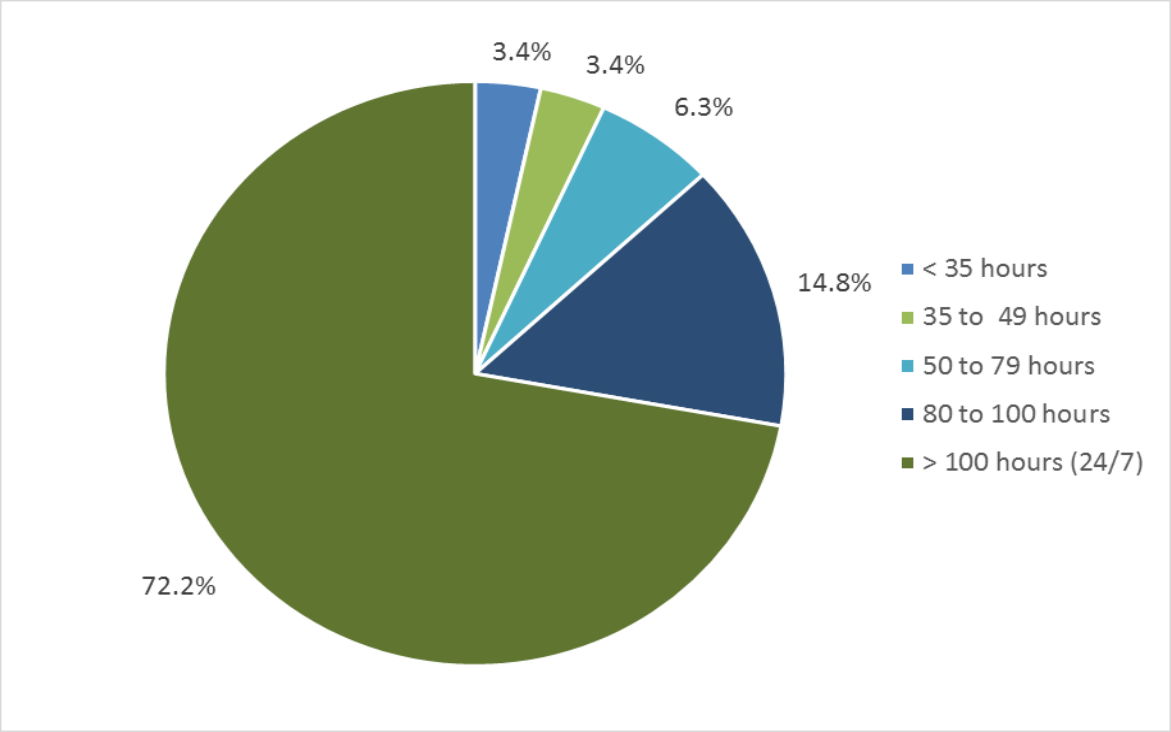

Figure 3.2 Hours of Care Provided in an Average Week

Carers in receipt of a Carer's Allowance are permitted by the DSP to engage in paid employment and/or study outside of the home for up to 15 hours a week. Table 3.2 shows that one in five carers (20.6%; 49/238) undertook paid work for up to 15 hours a week, while over three quarters (77.3%; 184/238) indicated that they did not engage in any paid work or study outside of the home. A very small proportion of respondents reported that they engaged in study for up to 15 hours a week (1.7%; 4/184), and only one respondent (0.4%; 1/238) reported that s/he engaged in both work and study.

Table 3.2 Carer's Allowance and Paid Work and/or Study

Type of Carer's Allowance	**% (n)**
Full-rate Carer's Allowance	69.4 (168)
Half-rate Carer's Allowance	28.1 (68)
Unsure/Don't know	2.5 (6)
Study or paid work (up to 15 hours a week) (N=238)	**% (n)**
Paid work up to 15 hours per week	20.6 (49)
Study up to 15 hours per week	1.7 (4)
Paid work and study up to 15 hours per week	0.4 (1)
None of the above	77.3 (184)

The survey included one question to ascertain the number of respondents who met the criteria of a 'compound carer'. Respondents were asked to indicate whether they 'provided regular unpaid care to another person requiring care, due to a long-term illness, disability, frailty or other impairment (e.g. to an elderly parent, a sibling with a physical disability etc.), in addition to the person with intellectual disabilities for whom they receive a Carer's Allowance'. As shown in Figure 3.3, over a quarter of carers (26.3%; 65/247) provided regular unpaid care to at least one other person, in addition to the care they provided to their relative with intellectual disability.

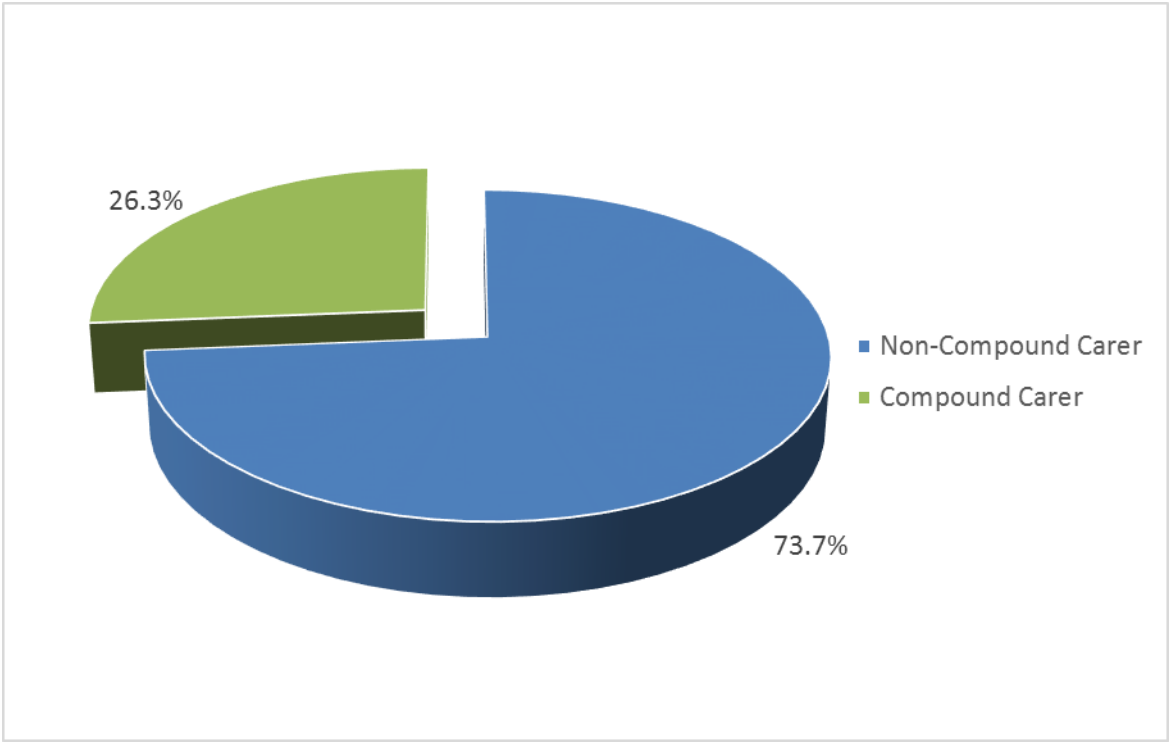

Figure 3.3 Proportion of Compound Carers

This group of compound carers (n = 65) were predominantly female (85.9%; 55/64) and aged 31 to 66 years, with an average age of 50 years (SD = 7.2). In addition to the full-time care they provided to the person with intellectual disability for whom they received a Carer's Allowance, over a third (37.5%; 24/64) also provided care to at least one parent or parent-in-law, while 35.9% (23/64) indicated that they also provided care to at least one child. The remaining compound carers provided care to another relative (25%; 16/64) or to a friend (1.2%; 1/64).

3.3 Profile of Care-recipients

The survey included a number of questions relating to the person with intellectual disability to whom the carer provided care. Respondents were asked to indicate the care-recipient's age, gender, level of intellectual disability, and frequency of

challenging behaviours. Findings show that the care-recipients were aged between 16 and 86 years, with an average age of 27 years (SD = 15.8; Median = 19 years; IQR = 15). The majority of care-recipients were male (70.4%; 171/243).

The Learning Disability Casemix Scale (LDCS) was used to rate the severity of intellectual disability and the frequency of challenging behaviours.[195] Scores on the LDCS range from 0 to 60 with higher scores indicating higher levels of intellectual disability and problem behaviours. In this study, overall scores ranged from 1 to 46 with an average score of 18.8 (SD = 9.1), indicating relatively low levels of intellectual disability and challenging behaviours among care-recipients.

The LDCS has two subscales: LDCS - Intellectual Disability and LDCS - Challenging Behaviours. Possible scores on the LDCS - Intellectual Disability subscale range from 0 to 39. In this study, scores ranged from 0 to 33 with a mean score of 14.9 (SD = 7.1), indicating that care-recipients had mild to moderate intellectual disabilities. Data analysis showed no statistically significant differences between male and female care-recipients in the LDCS - Intellectual Disability scores (U=3923, Z = .763, p = .44).

Table 3.3 presents the level of difficulty experienced by care-recipients with a range of physical, cognitive, and functioning aspects of intellectual disability. The main difficulty reported by 90.1% (219/243) of respondents was the care-recipients' difficulty with 'understanding money and numeracy'. Over half of these respondents (55.7%; 122/219) indicated that their relative experienced 'extreme difficulty'. The next most commonly reported difficulty was with 'language expression' (89.1%; 213/239), with almost two thirds (65.7%; 140/213) reporting that care-recipients experienced 'a lot of' or 'extreme difficulty' with this aspect. This was followed by difficulty with literacy (85.9%; 207/241), and difficulty with 'road sense' (83.9%; 203/242).

[195] Pendaries, C. (1997) Pilot study on the development of the learning disability healthcare resource groups. **British Journal of Learning Disabilities**, 25, 122–126.

Table 3.3 Level of Difficulty with Aspects of Intellectual Disability

	Not applicable	Applicable/ Level of difficulty		
Aspect of intellectual disability	% (n)	**Some difficulty** % (n)	**A lot of difficulty** % (n)	**Extreme difficulty** % (n)
Sight/vision	57.7 (135)	81.8 (81)	12.1 (12)	6.1 (6)
Hearing	76.1 (178)	71.4 (40)	19.6 (11)	8.9 (5)
Language comprehension	14.5 (35)	40.3 (83)	35.4 (73)	24.3 (50)
Language expression	10.9 (26)	34.3 (73)	35.7 (76)	30.0 (64)
Mobility	58.0 (141)	79.4 (81)	10.8 (11)	9.8 (10)
Toileting independently	65.7 (157)	53.7 (44)	28.0 (23)	18.3 (15)
Personal hygiene	28.7 (70)	51.7 (90)	23.6 (41)	24.7 (43)
Dressing independently	52.1 (126)	61.2 (71)	23.3 (27)	15.5 (18)
Eating/drinking independently	67.6 (163)	74.4 (58)	17.9 (14)	7.7 (6)
Understanding time	21.6 (53)	38.0 (73)	21.9 (42)	40.1 (77)
Understanding of money/numeracy	9.9 (24)	22.8 (50)	21.5 (47)	55.7 (122)
Literacy	14.1 (34)	30.0 (62)	26.1 (54)	44.0 (91)
Road sense (safety/flight risk)	16.1 (39)	31.0 (63)	23.2 (47)	45.8 (93)

Respondents were also asked to indicate the frequency with which care-recipients exhibited challenging behaviours. Possible scores on the LDSC - Challenging Behaviour subscale range from 0 to 21; data analysis showed that respondents' scores ranged from 0 to 18 with a mean score of 3.9 (SD = 3.6), implying low levels of challenging behaviours among care-recipients. While respondents indicated that male care-recipients (Mdn = 4.00) exhibited higher levels of challenging behaviour than females care-recipients (Mdn = 2.00), the difference was not statistically significantly different (U=7803, Z = 1.859, p = .06).

Table 3.4 shows that the most frequently reported behaviour exhibited by care-recipients was disruptive behaviour, such as throwing tantrums; this behaviour was exhibited by over two thirds of care-recipients (69.8%; 171/245). The next most commonly reported behaviours were repetitive behaviours (e.g. rocking and hand flapping), reported by over half of carers (56.6%; 138/244), and aggressive behaviours, such as hitting and screaming (50.2%; 124/247). Overall, the majority of carers who reported challenging behaviours exhibited by their care-recipient, indicated that these behaviours occurred 'sometimes'.

Table 3.4 Frequency of Challenging Behaviours

Frequency	Never % (n)	Sometimes % % (n)	Most of the time % (n)	All of the time % (n)
Offensive behaviours (e.g. underdressing/nudity in public)	72.1 (176)	22.1 (54)	3.3 (8)	2.5 (6)
Self-abusive behaviours (e.g. self-harming, head banging)	63.0 (153)	28.4 (69)	4.5 (11)	4.1 (10)
Aggression towards other people (e.g. hitting, screaming)	49.8 (123)	40.1 (99)	3.6 (9)	6.5 (16)
Destructive behaviours (e.g. causing damage to property)	61.9 (151)	29.5 (72)	5.3 (13)	3.3 (8)
Inappropriate sexual behaviours (e.g. masturbating in public)	91.0 (223)	7.3 (18)	0.8 (2)	0.8 (2)
Repetitive behaviours (e.g. rocking, hand flapping)	43.4 (106)	34.0 (83)	11.1 (27)	11.5 (28)
Disruptive behaviours (e.g. throwing tantrums)	30.2 (74)	51.8 (127)	10.2 (25)	7.8 (19)

3.4 Carers' Health and Psychological Wellbeing

The survey collected information on carers' general health and wellbeing. One questionnaire item asked respondents to describe their general health as poor, fair, good, very good, or excellent. Table 3.5 shows that overall, two thirds of respondents (66.0%; 159/241) rated their health as good, very good or excellent. Just over a third of carers (34.0%; 82/241) described their health as poor or fair. When comparing responses of self-reported health, a Mann Whitney test indicated that there was no significant difference between male and female carers (U = 3666, Z = 1.87, p = .06).

Table 3.5 Self-reported General Health

Characteristic	Total Sample % (n)	Female % (n)	Male % (n)	Z	P
Self-reported General Health				1.87	.06[ns]
Poor	**5.0 (12)**	5.6 (11)	2.2 (1)		
Fair	**29.0 (70)**	29.6 (58)	26.7 (12)		
Good	**43.6 (105)**	45.9 (90)	33.3 (15)		
Very Good	**19.5 (47)**	15.3 (30)	37.8 (17)		
Excellent	**2.9 (7)**	3.6 (7)	0.0 (0)		

[ns] Not significant

Carers' psychological health was assessed using the 12-item General Health Questionnaire (GHQ12).[196] Possible scores range from 0 to 12. Using a binary

[196] Goldberg, D.P. and Williams, P. (1988) **The user's guide to the general health questionnaire**. Windsor: NFER-Nelson.

format (0, 0, 1, 1), a GHQ12 score of 4 or above was used to identify respondents who were experiencing psychological distress. Overall, 40.8% of respondents (91/223) scored 4 or more on the GHQ12 scale, indicating that over two fifths of carers were experiencing some level of psychological distress (Figure 3.4). The mean score was 3.6 (SD =3.5) on the GHQ12.

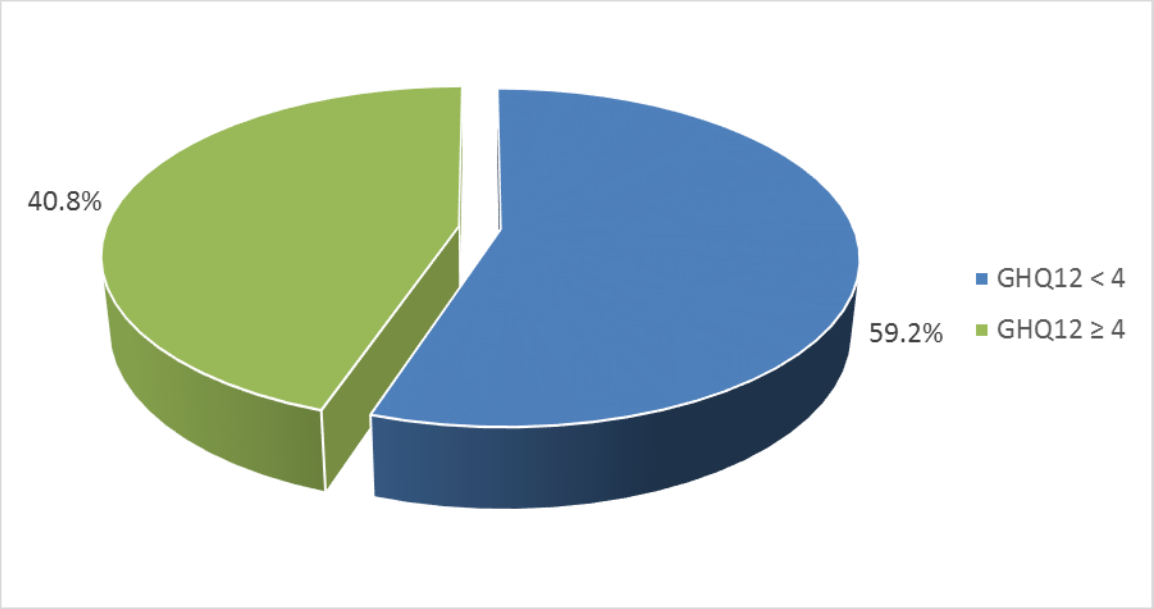

Figure 3.4 Carer Psychological Wellbeing

When comparisons were made between male and female respondents on the GHQ12, findings show that a statistically significantly higher proportion of females (44.7%; 80/179) experienced psychological distress than male carers (23.8%; 10/42) (Table 3.6).

Table 3.6 Carer Psychological Wellbeing by Gender

Characteristic	Female % (n)	Male % (n)	χ^2	P
Carer Psychological Wellbeing			6.15	.013*
GHQ12 Score < 4	55.3 (99)	76.2 (32)		
GHQ12 Score ≥ 4	44.7 (80)	23.8 (10)		

* Statistically significant at $p < 0.05$

There were no significant differences in responses between compound carers and non-compound carers, or between carer relationship type (parent, sibling, other) on the GHQ12.

3.5 Social Connectedness

The Social Connectedness Scale-Revised (SCS-R) measures social connectedness as a psychological sense of belonging and an interpersonal closeness with the social world.[197] Respondents were asked to indicate whether they agreed with 20 statements on a scale ranging from 1 (strongly disagree) to 6 (strongly agree). Possible scores range from 20 to 120. In this study, responses ranged from 37 to 120 with a mean of 82.0 (SD = 18.1). Figure 3.5 shows that almost three quarters of respondents (73%; 143/196) reported feeling socially connected, with 27% of respondents (53/196) reported feeling socially disconnected.

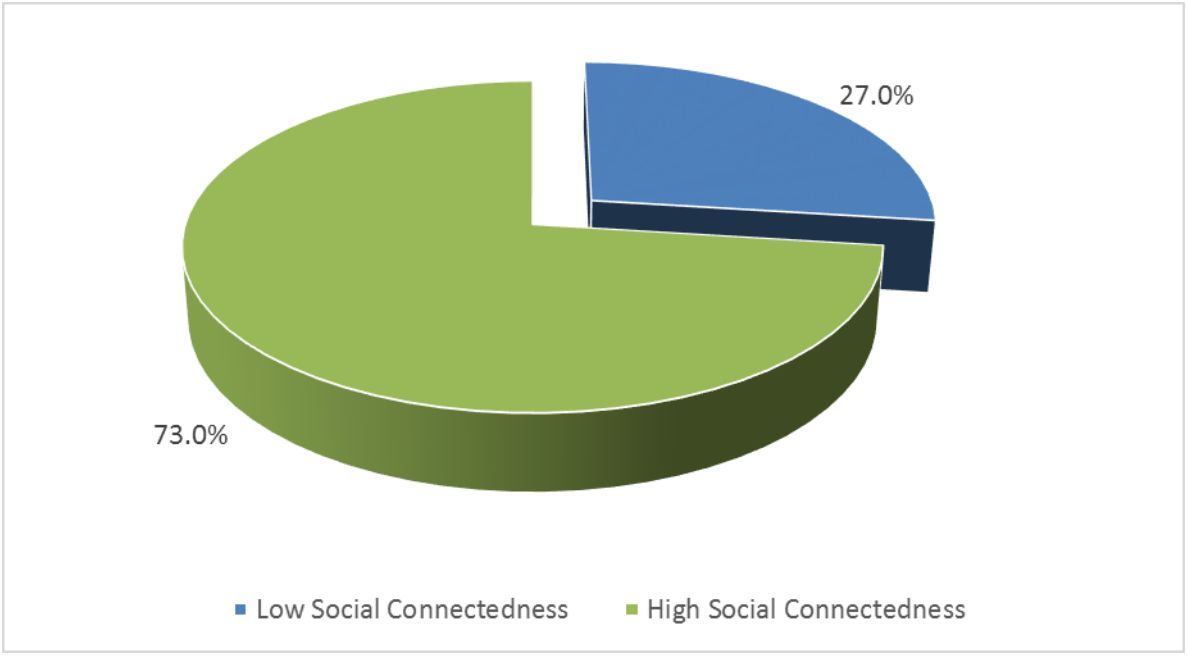

Figure 3.5 Social Connectedness

Male carers' scores were compared with female carers' scores on the SCS-R scale. Table 3.7 shows that there was no statistically significant association between gender and social connectedness [χ^2 (1, N = 195) = 0.13, p = .72].

[197] Lee, R. M., Draper, M., and Lee, S. (2001). Social connectedness, dysfunctional interpersonal behaviors, and psychological distress: Testing a mediator model. **Journal of Counselling Psychology**, 48, 310–318.

Table 3.7 Social Connectedness by Gender

	Male % (n)	Female % (n)	χ^2	p
Social Connectedness (SCS-R)			**0.13**	**.72[ns]**
Low Social Connectedness (mean score < 3.5)	28.9 (11)	26.1 (41)		
High Social Connectedness (mean score ≥ 3.5)	71.1 (27)	73.9 (116)		

[ns] Not significant at p > 0.05

Using a chi-square test, findings showed a statistically significant association between social connectedness and caregiving situation [χ^2 (1, N = 196) = 6.98, p = .008]. Non-compound carers (77.9%; 113/145) were significantly more likely to be socially connected than compound carers (58.8%; 30/145) (Table 3.8).

Table 3.8 Social Connectedness by Caregiving Situation

	Non-Compound Carer % (n)	Compound Carer % (n)	χ^2	p
Social Connectedness (SCS-R)			**6.98**	**.008[**]**
Low Social Connectedness (mean score < 3.5)	22.1 (32)	41.2 (21)		
High Social Connectedness (mean score ≥ 3.5)	77.9 (113)	58.8 (30)		

[**] Statistically significant at p < 0.01

3.6 Family Supports

In this study, respondents were asked several questions about the availability and helpfulness of family supports. The Family Support Scale (FSS) was used to assess the availability and helpfulness of family, friends, informal, and formal supports to carers and their families during the past three to six months.[198] Table 3.9 shows that the main sources of support available to respondents were their family GP (81.4%; 197/242), their other children (74.6%; 182/244), the respondents' friends (72.7%; 178/245), and relatives (72.5%; 177/244).

[198] Dunst, C.J., Jenkins, V. and Trivette C.M. (1984) The Family Support Scale: Reliability and validity. **Wellness Perspectives**, 1, 45–52.

Table 3.9 Source and Perceived Helpfulness of Family Support

	Non-applicable/ Not available	Applicable/Available		
		Not at all helpful	Sometimes helpful	Generally/ very/ extremely helpful
	% (n)	% (n)	% (n)	% (n)
My parents	61. 5 (150)	24.5 (23)	22.3 (21)	53.2 (50)
My partner	30.1 (72)	3.0 (5)	8.4 (14)	88.7 (148)
My partner's parents	70.0 (168)	43.1 (31)	22.2 (16)	34.7 (25)
My relatives	27.5 (67)	31.6 (56)	32.8 (58)	35.5 (63)
My partner's relatives	49.8 (119)	51.7 (62)	23.3 (28)	25.0 (30)
My friends	27.3 (67)	27.5 (49)	37.6 (67)	34.8 (62)
My partner's friends	56.3 (134)	55.8 (58)	21.2 (22)	23.0 (24)
My other children	25.4 (62)	4.4 (8)	22.5 (41)	73.1 (133)
Other carers	69.6 (165)	27.8 (20)	31.9 (23)	40.3 (29)
My neighbours	50.6 (123)	44.2 (53)	30.8 (37)	25.1 (30)
My co-workers/classmates	82.0 (200)	56.8 (25)	20.5 (9)	22.7 (10)
Carer/peer support groups	65.7 (161)	27.4 (23)	31.0 (26)	41.6 (35)
Social groups/clubs	61.0 (144)	23.9 (22)	29.3 (27)	46.7 (43)
Faith or religious supports	68.6 (166)	43.4 (33)	23.7 (18)	32.9 (25)
My family or my relative's general practitioner (GP)	18.6 (45)	8.1 (16)	33.5 (66)	58.4 (115)
School/college/day-care centre	35.8 (86)	8.4 (13)	11.7 (18)	79.9 (123)
Professional help (therapists, social workers, nursing staff)	34.7 (84)	20.3 (32)	31.0 (49)	48.7 (77)
Professional agencies (hospital, clinical, social services)	39.7 (96)	21.2 (31)	33.6 (49)	45.3 (66)

From the supports availed of by carers, their partner (88.7%; 148/167), school/college/day-centre (79.9%; 123/154), and their other children (73.1%; 133/182) were rated as the most (generally/very/extremely) helpful. The supports deemed 'not at all helpful' to carers were co-workers/classmates (56.8%; 25/44), their partner's friends (55.8%; 58/104), and their partner's relatives (51.7%; 62/120).

3.7 Professional Services

A revised version of the Client Services Receipt Inventory (CSRI) was used to collect information about the range of multidisciplinary support services required by carers during the preceding six months.[199] Respondents were also asked to indicate whether they received the service and whether they thought it was 'helpful' or 'not helpful'.

Table 3.10 presents carers' responses and shows that the most commonly required services reported by family carers were the GP (78.4%; 192/245), and dental services (57.3%; 138/241), followed by psychological counselling services (42.6%; 101/237). While the vast majority of carers indicated that they received GP and dental services, of those who required psychological/counselling services, just over a third of carers indicated that did not receive the service (37.5%; 36/96).

Respondents indicated that the service required the least in the previous 6 months was 'meals on wheels' (3.0%; 7/234), followed by specialist services (e.g. Clinical Nurse Specialist) (11.4%; 27/237), and crisis respite care (11.9%; 28/235). Of those carers who reported that they required crisis respite care in the preceding six months, just over half (57.7%; 15/26) indicated that they did not receive the service. Similarly, more than one in five carers (21.1%; 48/228) indicated that they needed alternative therapies (e.g. sensory therapy) in the preceding six months. Of these carers, 61.9% (26/42) reported that they did not receive the service. Half of the respondents who reported that they required dietician services and home-based respite services indicated that they had not received the service. Despite requiring occupational therapy, just under half of the respondents reported that they had not received this service in the preceding six months.

The vast majority of respondents indicated that they found the services they received helpful. All of the carers who reported receiving the following services in the previous six months deemed them 'helpful': centre-based respite (n=30); day care (n=43); optician services (n=53) and alternative therapies (n=13). The other main services deemed helpful were dental services (99.0%; 97/98), planned respite care (98.1%; 53/54), and chiropody services (96.8%; 30/34). Four out of eleven carers who received crisis respite care reported it as unhelpful, while a quarter of carers (25.6%; 11/43) who received psychiatry services deemed this service unhelpful. Two out of the three carers who received 'meals on wheels' reported that the service was 'unhelpful'.

[199] Beecham, J. (1995) Collecting and Estimating Costs. In M.R.J. Knapp (ed.) **The Economic Evaluation of Mental Health Care.** Aldershot: Arena.

Table 3.10 Required, Received, and Perceived Helpfulness of Services in Preceding 6 Months

Services	Services Required		Services Received		Helpfulness	
	Did not require the service % (n)	Required the service % (n)	Did not receive the service % (n)	Received the service % (n)	Not helpful % (n)	Helpful % (n)
General practitioner (GP) services	21.6 (53)	78.4 (192)	1.2 (2)	98.8 (169)	3.8 (6)	96.2 (151)
Public health nursing	81.4 (193)	18.6 (44)	19.0 (8)	81.0 (34)	12.9 (4)	87.1 (27)
Social work	69.4 (161)	30.6 (71)	20.0 (14)	80.0 (56)	21.3 (10)	78.7 (37)
Speech and language therapy	65.1 (155)	34.9 (83)	34.2 (27)	65.8 (52)	15.6 (7)	84.4 (38)
Psychological/counselling services	57.4 (136)	42.6 (101)	37.5 (36)	62.5 (60)	11.3 (6)	88.7 (47)
Occupational therapy	64.3 (153)	35.7 (85)	46.8 (37)	53.2 (42)	21.1 (8)	78.9 (30)
Physiotherapy services	75.9 (176)	24.1 (56)	43.6 (24)	56.4 (31)	13.8 (4)	86.2 (25)
Psychiatry services	69.1 (163)	30.9 (73)	37.7 (26)	62.3 (43)	25.6 (11)	74.4 (32)
Dietician services	80.5 (190)	19.5 (46)	50.0 (20)	50.0 (20)	16.7 (3)	83.3 (15)
Respite care – planned	63.6 (152)	36.4 (87)	28.6 (24)	71.4 (60)	1.9 (1)	98.1 (53)
Respite care – crisis	88.1 (207)	11.9 (28)	57.7 (15)	42.3 (11)	36.4 (4)	63.6 (7)
A centre-based respite service	75.7 (178)	24.3 (57)	35.8 (19)	64.2 (34)	0.0 (0)	100.0 (30)
A home-based respite service	85.2 (202)	14.8 (35)	50.0 (17)	50.0 (17)	20.0 (3)	80.0 (12)
Personal care attendant/ home help	80.2 (190)	19.8 (47)	43.2 (19)	56.8 (25)	5.0 (1)	95.0 (19)
Support worker	70.6 (166)	29.4 (69)	39.7 (25)	60.3 (38)	11.8 (4)	88.2 (30)
Optician services	67.2 (156)	32.8 (76)	18.1 (13)	81.9 (59)	0.0 (0)	100.0 (53)
Alternative therapies (e.g. sensory therapy)	78.9 (180)	21.1 (48)	61.9 (26)	38.1 (16)	0.0 (0)	100.0 (13)
Dental services	42.7 (103)	57.3 (138)	7.9 (10)	92.1 (116)	1.0 (1)	99.0 (97)
Hearing services	82.9 (194)	17.1 (40)	18.9 (7)	81.1 (30)	3.6 (1)	96.4 (27)
Chiropody services	78.2 (187)	21.8 (52)	27.7 (13)	72.3 (34)	3.2 (1)	96.8 (30)
Day hospital/out-patient	72.5 (174)	27.5 (66)	4.9 (3)	95.1 (58)	7.1 (4)	92.9 (52)
Specialist services e.g. Clinical Nurse Specialist (CNS)	88.6 (210)	11.4 (27)	8.0 (2)	92.0 (23)	13.0 (3)	87.0 (20)
Day care centre	75.7 (174)	24.3 (56)	13.0 (7)	87.0 (47)	0.0 (0)	100.0 (43)
Vocational training/adult education (e.g. FETAC)	72.6 (172)	27.4 (65)	20.0 (12)	80.0 (48)	9.5 (4)	90.5 (38)
Sheltered/supported employment	85.5 (195)	14.5 (33)	34.5 (10)	65.5 (19)	11.1 (2)	88.9 (16)
Meals on wheels	97.0 (227)	3.0 (7)	42.9 (3)	57.1 (4)	66.7 (2)	33.3 (1)

3.8 Internet-based Supports

Respondents were asked to indicate the level of usefulness of internet-based technology (e.g. computer, tablet, mobile phone, apps etc.) as it applied to their caregiving role. Table 3.11 shows that, of those carers who responded that they used these technologies, the majority reported that they were 'generally/very/extremely useful' for connecting with friends (66.1%; 123/186) and family (65.4%; 123/188), as well as with formal resources and services (62.4%; 108/173). Over a quarter of carers (26.1%, 29/111) indicated that internet-based technologies were 'not at all useful' to them to connect with other carers.

Table 3.11 Perceived Usefulness of Internet-based Technologies to Connect with Others

	Non-applicable/ Not available	Applicable/Available		
How useful is internet-based technology to you to…	**% (n)**	**Not at all useful % (n)**	**Sometimes useful % (n)**	**Generally/ very/ extremely useful % (n)**
Connect with family members	22.6 (55)	8.0 (15)	26.6 (50)	65.4 (123)
Connect with friends	22.8 (55)	8.6 (16)	25.3 (47)	66.1 (123)
Connect with other carers	52.6 (123)	26.1 (29)	26.1 (29)	47.7 (53)
Connect with formal resources and services	29.1 (71)	9.8 (17)	27.7 (48)	62.4 (108)

Just over half of carers (51.6%; 79/153) who availed of internet-based technologies in their caregiving role responded that they used them to seek advice about the care of their relative with intellectual disabilities. While 14.4% (22/152) of carers reported that the internet was not useful for this purpose (Table 3.12). Over a third of carers (35.0%; 43/123) indicated that the internet was not useful for venting/offloading about the challenges associated with caregiving, or for making future plans for the care of their relative with intellectual disabilities (31.3%; 42/134). In addition, a small number of carers reported that they also used internet technology for the purpose of day care, to access general information on disabilities and therapies, to read about other carers' in a similar situation, to look up entitlements for the person with intellectual disabilities, and to order supplies and resources such as books.

Table 3.12 Perceived Usefulness of Internet-based Technologies to Support Caregiving

	Non-applicable/ Not available	Applicable/Available		
How useful is internet-based technology to you to…	**% (n)**	**Not at all useful % (n)**	**Sometimes useful % (n)**	**Generally/ very/ extremely useful % (n)**
Share experiences and advice about the care of your relative with ID	39.3 (96)	20.3 (30)	33.1 (49)	46.6 (69)
Seek advice about the care for your relative with ID	36.5 (88)	14.4 (22)	34.0 (52)	51.6 (79)
Express (vent/offload) the challenges associated with caregiving	48.8 (117)	35.0 (43)	22.8 (28)	42.3 (52)
Make future plans for the care of your relative with ID	44.2 (106)	31.3 (42)	21.6 (29)	47.0 (63)

3.9 Carer Resilience

Carer resilience was measured using the Resilience Scale for Adults (RSA).[200] Possible scores ranged from 33 to 165, while higher scores imply higher levels of resilience. Respondents' scores ranged from 60 to 165 with a mean of 116.5 (SD = 21.8), suggesting that carers were relatively resilient.

Table 3.13 presents findings from independent samples t-tests, conducted to calculate differences between groups of carers. Findings show that male carers scored higher on the RSA (M =122.5, SD = 21.4) than female carers (M =115.1, SD = 21.8), however the difference was not statistically significant [$t(204) = 1.91$, $p = .06$].

Responses to the questions on carers' marital status were grouped into 'married/civil partnership' and 'not married'. Findings showed that there was no statistically significant difference between the carer groups in carer resilience [$t(204) = 1.06$, $p = .29$]. Also, there was no significant difference in carer resilience between carers with a non-third level education (Junior/Leaving Cert/Vocational education) and those with a third-level education (Cert/Dip/Bachelor's/Master's Doctoral) [$t(201) = 0.59$, $p = .56$].

[200] Friborg, O., Barlaug, D., Martinusssen, M., Rosenvinge, J.H. and Hjemdal, O. (2005) Resilience in relation to personality and intelligence. **International Journal of Methods in Psychiatric Research**, 14 (1), 29–42.

Resilience scores for respondents of male care-recipients (M = 118.2, SD = 21.2) did not differ significantly compared to those who cared for female care-recipients (M = 113.0, SD = 22.8) [t(206) = 1.57, p = .12].

Table 3.13 Factors Associated with Carer Resilience

	Mean (M)	Standard Deviation (SD)	t	p
Carer Gender			**1.91**	**.06^{ns}**
Male	122.5	21.4		
Female	115.1	21.8		
Carer Marital Status			**1.06**	**.29^{ns}**
Married/Civil partnership	118.1	21.0		
Not married/Civil partnership	114.8	23.0		
Carer Education			**0.59**	**.56^{ns}**
Non-third level education	115.9	21.8		
Third level education	118.2	22.6		
Care-recipient Gender			**1.57**	**.12^{ns}**
Male Care-recipient	118.2	21.2		
Female Care-recipient	113.0	22.8		
Compound Caregiving			**2.50**	**.013***
Non-compound Carer	118.9	22.3		
Compound Carer	110.7	19.7		
Living Arrangements			**2.46**	**.015***
Lives with the care-recipient	115.6	21.6		
Does not live with the care-recipient	129.9	18.2		
Location			**1.47**	**.14^{ns}**
Rural (< 1500 people)	114.2	22.7		
Urban (> 1500 people)	118.7	21.1		
Carer Psychological Health			**8.41**	**< .001*****
Low Psychological Distress	125.9	18.0		
High Psychological Distress	103.1	19.4		
Carer General Health			**4.93**	**< .001*****
Poor/Fair	106.5	18.5		
Good/Very good/Excellent	121.5	21.8		
Carer Social Connectedness			**9.48**	**< .001*****
Low Social Connectedness	96.5	17.4		
High Social Connectedness	124.8	17.7		

^{ns} Not significant at $p > 0.05$
* Statistically significant at $p < 0.05$
*** Statistically significant at $p < 0.001$
[a] Scores on the RSA range from 33 to 165 with higher scores indicating higher levels of resilience

When compared with non-compound carers, findings on the RSA showed that compound carers had significantly lower resilience scores than non-compound carers [t(207) = 2.50, p = .013].

Carers who reported that they did not live with their care-recipient scored higher in resilience (M = 129.9, SD = 18.2) than carers who lived with the care-recipient (M = 115.6, SD = 21.9) [t(204) = 2.46, p = .015].

Data analysis, comparing carers who resided in rural and urban areas, showed that there was no significant difference between the two carer groups on resilience scores [t(205) = 1.47, p = .14].

An independent samples t-test showed that respondents who had high levels of psychological distress (GHQ12 score ≥ 4), scored significantly lower in resilience (M = 103.1; SD = 19.4), when compared to respondents who had low levels of psychological distress (GHQ scores < 4) (M = 125.9, SD = 18.0) [t(191) = 8.41 p < .001].

Carers' self-reports of general health were grouped into 'poor and fair' and 'good, very good, and excellent'. A comparison of these two groups showed that carers who rated their health as 'poor/fair' scored lower in resilience (M = 106.5, SD = 18.5), than carers who rated their health as 'good/very good/excellent' (M = 121.5, SD = 21.8) [t(205) = 4.93, p < .001].

Social connectedness was found to be associated with carer resilience. A comparison between carers with low levels of social connectedness and those with high levels of social connectedness revealed that carers who were less socially connected were less resilience (M = 96.5, SD = 17.4), than carers who were more socially connected (M = 124.8, SD = 17) [t(173) = 9.48, p < .001].

Using a One-way ANOVA, data analysis showed that there were no significant differences in carer resilience between the following three carer groups: parent, sibling and other relative [F(2, 198) = 1.99, p = .14]. Similarly, there were no significant differences between the following carer age groups: < 46 years, 46 to 55 years, 56 to 64 years, 65 years and older [F(3, 197) = 1.86, p = .14]. The number of hours of care provided by carers was also not associated with carer resilience.

Table 3.14 presents findings from Spearman's rho correlation test, which was conducted to test for relationships between carer resilience and independent variables relating to carers, caregiving, and care-recipients. Data analysis revealed that carer resilience was negatively correlated with overall LDCS scores [r(169) = -.188, p < .05], as well as for the LDSC subscale relating to challenging behaviours [r(201) = -.261, p < .001]. However, there was no correlation between carer resilience and the LDCS subscale relating to intellectual disability [r(176) = -.120, p > .05]. This suggests that low levels of resilience among carers is linked with high levels of challenging behaviour among care-recipients.

Findings also showed a positive correlation between carer resilience and the perceived helpfulness of overall family support. Indicating that as levels of perceived helpfulness of family support increased, so too did the level of carer resilience (r(179) = .274, p < .001). This relationship was also statistically significant for each of

the subscales relating to formal supports, family support, and other informal supports.

Findings suggest that there is no statistically significant relationship between carer resilience and the following variables: carers' age, the care-recipients' age, level of intellectual disability (excluding challenging behaviours), and the number of years providing care.

Table 3.14 Correlations between Carer Resilience Scores and Caregiving Variables

Variable	r	n	p
Carers' Age	.127	201	.072[ns]
CRs' Age	.131	207	.059[ns]
Care-recipients' LDCS Tot (ID & Chan Behs)	-.188	169	.015[*]
Care-recipients' Level of Intellectual Disability (LDCS subscale)	-.120	176	.113[ns]
Care-recipients' Challenging Behaviours (LDCS subscale)	-.261	201	< .000[***]
Number of years providing care	-.059	184	.429[ns]
Family Support Scale (FSS) Total	.274	179	.000[***]
Perceived helpfulness of formal support (FSS subscale)	.144	197	.044[*]
Perceived helpfulness of family support (FSS subscale)	.193	197	.007[**]
Perceived helpfulness of other informal support (FSS subscale)	.252	189	< .000[***]

[ns] Not significant at p > 0.05
[*] Statistically significant at p < 0.05
[**] Statistically significant at p < 0.01
[***] Statistically significant at p < 0.001

3.10 Summary

This chapter presented the profile of 247 family carers who participated in the postal survey, Phase 1 of the study. Findings showed that the vast majority of respondents were female and Irish. Respondents were aged between 24 and 86 years. Over half of carers reported that they were married and/or in a civil partnership. Just 5.9% of participants had completed a third level degree (Bachelors/Master/Doctoral degree). The vast majority of respondents lived with their relative with intellectual disability, for whom they received a Carer's Allowance. Over two thirds of participants identified themselves as a mother of a person with intellectual disability and/or autism, while approximately one in seven carers was a father, and just over one in ten was a sibling carer to a person with intellectual disability and/or autism. Over half of carers lived in an urban area, with a population of more than 1,500 people.

On average, carers' reports indicated that they had been providing care for 15 years, with almost three quarters reporting that they provided care for more than 100 hours a week, suggesting that they provided care for 24 hours a day, 7 days a week. Over two thirds of respondents reported that they received a full-rate Carer's

Allowance, while just six respondents indicated that they were unsure which type of Carer's Allowance they received. Over three quarters of respondents did not work or study outside of the home. One fifth engaged in work for up to 15 hours a week, four respondents indicated that they studied, and one respondent engaged in work and study for up to 15 hours a weeks.

More than a quarter of respondents indicated that they were a compound carer, providing regular unpaid help to a person requiring full-time care, in addition to the person with intellectual disability for whom they received a Carer's Allowance. Respondents identifying themselves as compound carers were predominantly female, aged 31 to 66 years and the second person to whom they provided care was mainly a parent/parent-in-law or a child.

Information was also collected from respondents about the profile of their care-recipients with intellectual disability and/or autism. Findings showed that care-recipients were predominantly male, aged between 16 and 86 years, with an average age of 19 years. Findings suggested that most care-recipients had mild to moderate levels of intellectual disability, with the majority of care-recipients experiencing difficulty with understanding money and numeracy, language expression, literacy and road safety. Data analysis also suggested that care-recipients had relatively low levels of challenging behaviours. While male care-recipients exhibited higher levels of challenging behaviour than female care-recipients, there was no significant difference. The most frequent types of challenging behaviours exhibited by care-recipients were disruptive behaviours, which were reported by over two thirds of carers, followed by repetitive behaviours and aggressive behaviours, which were reported by over half of carers.

Furthermore, the survey collected information on respondents' health and wellbeing. Two thirds of respondents reported that their general health was good, very good, or excellent. Approximately two in five respondents scored above the threshold for psychological distress. There was a significant difference between genders, with more female carers scoring above the threshold for psychological distress.

Almost three quarters of carers were categorised as highly socially connected. There was no difference in social connectedness between male and female carers. Compound carers were significantly more like to be less socially connected than non-compound carers.

Respondents reported that the main sources of support available to them and their family in the preceding three to six months were their family GP, their other children, as well as their relatives and friends. From the supports availed of by respondents, their partner, followed by school/college/day centre, and their other children were rated as the most helpful sources of support.

In the preceding six months, the main services required by respondents were the GP, dental, and psychological/counselling services. The vast majority of respondents indicated that they received GP and dental services, however over a third indicated

that they did not receive psychological services. Of those respondents who reported that they required crisis respite care in the preceding 6 months, just over half indicated that they did not receive this service. More than one in five respondents indicated that they required alternative therapies for the care-recipient in the previous six months, however, again the majority of respondents reported that they did not receive this service. Of those who received the following services, all of the respondents deemed them to be 'helpful': centre-based respite, day care, optician services, and alternative therapies. The vast majority also deemed dental services, planned respite care, and chiropody services to be 'helpful'. Only a small number of respondents (n = 11) indicated that they received crisis respite care, but of those who received it, over a third reported it to be 'unhelpful', while a quarter of carers, whose care-recipient received psychiatry services, deemed these services to be unhelpful. The majority of respondents indicated that the internet was a useful platform for connecting with friends, family, as well as formal resources and services.

Findings suggested that respondents were relatively resilient. A number of independent factors were significantly associated with low carer resilience including being a compound carer, living with the care-recipient with intellectual disability, having high psychological distress, self-reporting poor/fair general health, and having low levels of social connectedness. Findings also revealed that low carer resilience was related to care-recipients exhibiting high levels of challenging behaviours as well as having low levels of family support from family, other informal, and formal supports.

Chapter 4: Findings Phase 2 - Telephone Interviews with Compound Carers

The purpose of Phase 2 was to explore the compound caregiving experience of family carers of a person with intellectual disability and/or autism. For the purposes of this study, a 'compound carer' was considered 'a person who provided regular unpaid care to another person requiring care, due to a long-term illness, disability, frailty or other impairment e.g. to an elderly parent, a sibling with a physical disability etc., in addition to the person with intellectual disability for whom they received a Carer's Allowance'. Carers who fulfilled this criterion were invited to participate in a telephone interview. There was overwhelming interest from the survey population of carers wishing to participate in this phase of the study. Due to the underrepresentation of males in caregiving, male carers were purposively contacted first for interviews. The remaining interviewees were purposefully selected at random based on geographical location. This chapter summarises the characteristics of the compound carers and presents the findings under three main themes: 'Divisions of Compound Caring', 'Learning and Transitioning', and 'Maintaining and Sustaining Continuity of Care'; which have been further analysed into six subthemes: 'Compartmentalisation'; 'Embodiment of Care'; 'Preparedness and Readiness'; 'Acceptance and Adaptation'; 'Insular Approaches to Care'; and 'Refuge Outside of Caring' (Figure 4.1).

4.1 Characteristics of Compound Carers

A total of 14 interviews were conducted with 4 male and 10 female compound carers who met the study's eligibility criteria. Participants were located throughout 12 counties in the Republic of Ireland. Compound carers' age ranged from 38 to 65 years, with an average age of 51 years. Participants reported that they had been compound caring for an average of 5.1 years, providing care for any length of time ranging from 1 to 14 years.

Eleven of the participants were Irish, two were of other European nationalities, and one was non-European. Half of the participants were married and/or living with a partner, and the other half were either single, widowed, or separated and living alone. The majority of the interview participants were living in an urban area (n=9) with the remaining (n=5) living in a rural area.

All of the compound carers who participated in a telephone interview were caring for a person with intellectual disability as their primary care-recipient. The majority were caring for their child with intellectual disability (n=10), and the remaining were caring for a sibling with intellectual disability (n=4). The care-recipients with intellectual disability and/or autism were aged 16 to 58 years, with a median age of 20 years. Secondary care-recipients were more varied in age, ranging from 11 to 95 years, with a median age of 32 years.

Table 4.1 summarises the 14 participants' compound caregiving situations. These were grouped into three distinct compound carer categories. The first category is the 'Parental Compound Carer', which include carers who provide full-time care for a son or daughter with intellectual disability (primary care-recipient) and regular unpaid care to another relative(s) (secondary care-recipient(s)). The second category is the 'Sandwich Compound Carer' and includes carers who provide full-time care for a son or daughter with intellectual disability and regular unpaid care to a mother/in-law or father/in-law. The third category is the 'Sibling Compound Carer'; these carers provide full-time care to a brother or sister with intellectual disability and regular unpaid care to another relative/friend. Within these categories, there are still many unique circumstances and diverse compound caring situations (Table 4.1).

Table 4.1 Types of Compound Caregiving Situations

No.	Participant Details*:	Cares for: (primary care-recipient)	Compound Cares for: (secondary care-recipient(s))
		Parental Compound Carer	
1	Female, married	Daughter with ID	Son with ID and son with epilepsy
2	Male, married	Son with ID/Autism	Son with ID/autism
3	Female, widowed	Son with ID/ Cerebral Palsy	Son with Asperger's syndrome
4	Female, separated	Daughter ID	Son with dyspraxia and daughter with DCD
5	Female, separated	Son with ID	Daughter with autism
6	Female, married	Son with ID	Husband with chronic illness and physical disability
		Sandwich Compound Carer	
7	Female, married	Son with ID/autism	Mother-in-law with dementia
8	Female, separated	Son with ID/autism	Mother with MCI
9	Male, married	Daughter with ID	Mother with chronic illness
10	Female, married	Daughter with ID	Mother with chronic illness
		Sibling Compound Carer	
11	Female, single	Brother with ID/ depression	Friend with psychological issues
12	Male, separated	Sister with ID	Brother with ID
13	Male, lives w/partner	Brother with ID	Brother with schizophrenia
14	Female, separated	Brother with ID	Mother with dementia

ID – Intellectual Disability; DCD – Developmental Coordination Disorder; MCI – Mild Cognitive Impairment

* Participant details are scant to protect their identify

4.2 Overview of Themes and Subthemes

The compound carer interviews indicated that carers found themselves 'in between worlds'. Findings are presented in three main themes, namely the 'Divisions of Compound Caring', 'Learning and Transitioning', and 'Maintaining and Sustaining Continuity of Care' (Figure 4.1). These themes relate to the context, processes, and outcomes of compound carers' experiences. The first theme, 'Divisions of Compound Caring', situates carers in the context of their dynamic and compound caring circumstances. The second theme, 'Learning and Transitioning', describes the fluid processes experienced by carers when responding to the inevitable changes associated with compound caring. The third theme, 'Maintaining and Sustaining Continuity of Care', relates to the outcomes of the compound caring circumstances and carers' drive to strive for maintenance and balance of continued care.

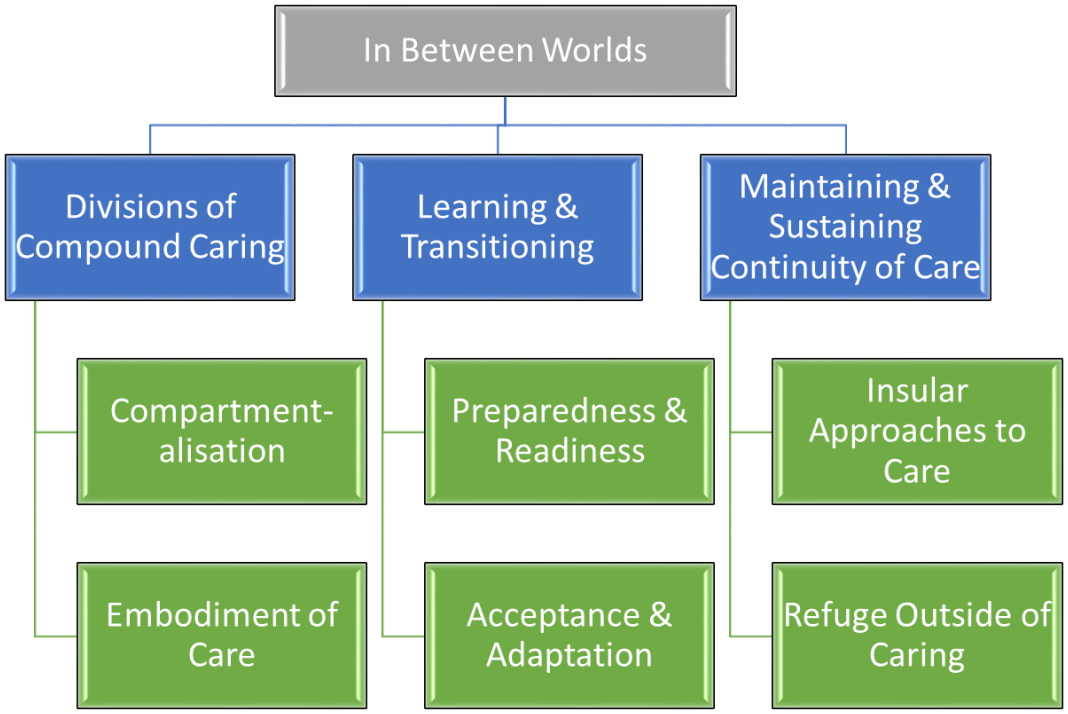

Figure 4.1 Overview of Themes and Subthemes

4.3 Divisions of Compound Caring

The first main theme, 'Divisions of Compound Caring', relates to the carer's situation in the context of their compound caregiving circumstances and their approaches to managing compound care (Figure 4.2). This theme presents the following two subthemes: 'Compartmentalisation' and 'Embodiment of Care'. Interviews with carers revealed experiences of compound caring that spanned across a spectrum, with approaches to compound caring ranging from distinct to indiscernible. At one end of the spectrum, approaches to compound caring seemed distinctly focussed on compartmentalising everyday tasks and responsibilities, while at the other end of the spectrum, approaches appeared to focus on the embodiment of

care, in so much that discerning the carer's themselves from their caring situations was far more difficult.

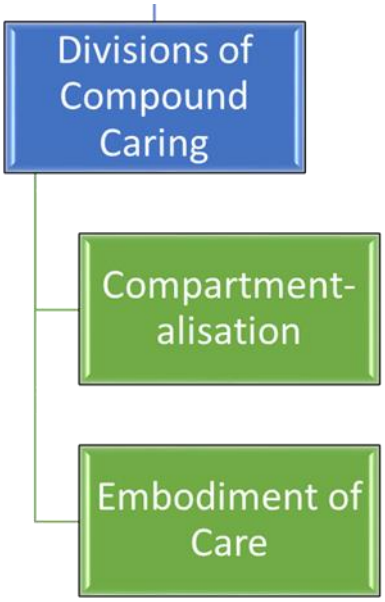

Figure 4.2 Divisions of Compound Caring

Compartmentalisation

Participants spoke about their approaches to caregiving and revealed a range of strategies used to adapt, control, and manage their current compound caring circumstances. Compartmentalisation was seen as the discrete division of caring responsibilities, and permitted distinct boundaries of 'self' and 'circumstances' to form within the compound carer's role and identity. However, the extent of these boundaries varied from carer to carer. While in some instances they were distinct, in other situations they were indiscernible. While some carers had difficulty distinguishing between their caring roles and responsibilities, it was found that others had explicitly created separations of caring roles and responsibilities.

This approach appeared to be adopted when care-recipients had very different caring needs. Compartmentalisation meant making clear distinctions in the management and the provision of care in order to meet the needs of each care-recipient. In some circumstances, compartmentalisation was not a choice, but rather it was a necessity. One sandwich carer spoke about her predicament of caring for her 18 year old son with intellectual disability, as well as an ageing mother-in-law with dementia, and explained why there was a need to compartmentalise their care:

> There's no way she'd [mother in-law] come before him [son with ID]. Well there was one time when she had to go to A and E for something, I forget, and I had to pick him up from school and bring both of them into A and E, and I swore that day that I was never doing anything like that again. Because she was

> slow and he was fast … I said that day, I didn't care, that there was no way I was ever having the two of them together again, ever.
>
> [Compound Carer 7]

Another sandwich carer for a son with intellectual disability and autism, as well as a mother with mild cognitive impairment, described the separation and organization of compound tasks and schedules:

> I sort of can balance now between the two of them. When (my son with ID) has gone to school and he's washed and cleaned and stuff, then I can attend to her [Mother] … it's just kind of half and half, balance it out.
>
> [Compound Carer 8]

Some participants spoke about sharing the responsibility of caring for a second care-recipient, an older mother with chronic illness, through the division of caring responsibilities with other siblings and caring supports:

> I suppose it's hard sometimes with my sister that lives at home [with my mother]. She works full time and between us we're mostly managing her hours but sometimes one of us might need to change something, something might come up at work and it doesn't always work out and it doesn't really cause friction but I suppose it can make things a bit more difficult. But we're lucky that we are a very close family, so yeah between the three of us.
>
> [Compound Carer 10]

Participants shared sentiments for the importance of having established caregiving spaces and environments. Given that it was more common for carers to live with their primary care-recipient, if not both of their care-recipients, this desire for separate space and time apart was not always feasible and sometimes difficult to realise. Carers who did not reside with their secondary (or in some cases even their primary) care-recipient highlighted this distinction. One sibling caring for her brother with intellectual disability, as well as and her mother with dementia, described how she managed her role as a compound carer through the separation of her own time and space:

> The weekdays is totally committed to the two of them [care-recipients], because I still go to the hospital and collect [my mother's] washing and that, and with [my brother with ID] on the weekends then sometimes I'd bring him down [to my house], and I don't really mind. But I'm happy in my own home and I'm happy with what I do, like read or I'd look at a film, and I'm happy with that.
>
> [Compound Carer 14]

Embodiment of Care

Carers' ability to situate themselves and identify the boundaries of their caring circumstances varied from carer to carer. Divisions of compound caring ranged from

distinct to indiscernible. Carers demonstrated difficulty distinguishing their own identity from their compound caring identities sometimes, and instead, appeared to fully embody their caregiving situation. This became evident as the interviews progressed and as participants struggled to dissociate their own experiences, perspectives, and aspirations from those of their care-recipients.

One parental carer of two adolescent sons with intellectual disability and autism was asked about his own aspirations for the future. From this response it was evident that his own aspirations were entwined in both his compound caregiving role and his parental role:

> As regards our own set up, it's basically overwhelmingly geared towards our two special needs sons. I would love to go back to work realistically, just for myself, but really that can't be done at the moment, it simply just can't happen … We'd obviously have the same aspirations as most parents have. We're obviously very tampered because of our situation, but for ourselves and our kids you know, it's just you have to.
>
> [Compound Carer 2]

One sibling carer of two adult brothers described his own struggle to distinguish his identity from his caring situation. He spoke of the conflict he experienced between perceived family responsibilities and what could potentially be an indefinite suspension of his own personal aspirations and career oriented goals:

> I suppose knowing whether I could still have a career. Not knowing it is kind of, the thoughts of … for want of a better word, 'stuck' not a word I want to use, but that is probably the easiest one to get my point across … doing this for the rest of my life is not appealing. And again it's not because I've no interest in looking after my family, obviously I do, but obviously when you set off in life you want a career ... I've been working since I was 15 so I'm so used to working, and then not being able to do that it gets frustrating.
>
> [Compound Carer 13]

Carers conveyed a notion of complete immersion and embodiment in their compound caring situation. Many carers indicated that they sometimes suspended aspects of their own lives, to a point where personal goals and aspirations might begin to disappear. One participant caring for her brother with intellectual disability, as well as her mother with dementia, expressed difficulty discerning and prioritising other family members outside of her compound caring situation. She spoke about the impact this had on her nuclear family unit:

> [My life] absolutely changed, completely, because as I said I was working and I had to give up my own job and it caused hassles between myself and my own children in the beginning because you know they'd say you spend all your time there [at care-recipient's] and you're prioritising them [both care-recipients]. And they were telling the truth, I was forgetting about my own, even though the two bigger ones you know were adults. But [my youngest son] was only very young, 13, and it had an awful effect on him…an awful, awful effect.

[Compound Carer 14]

A mother of three children with intellectual and developmental disabilities spoke about how she embodied her caregiving role, to a point that it impacted on her marriage:

> I've always put my kids first, my marriage, it broke down, so be it … if he wasn't able to put up with it … We have our ups, we have our downs but at the end of the day the kids are there for a reason and they will always be my number one priority … they will always come before me and any man in this world.
>
> [Compound Carer 4]

4.4 Learning and Transitioning

The second theme, 'Learning and Transitioning', describes the processes experienced by carers when responding to, and engaging in, their compound caring role. Despite differences in carers' circumstances, such as when carers commenced their compound caregiving responsibilities and the length of time they have been providing care to two or more care-recipients, all participants spoke about their experiences transitioning and learning. Inherent in these processes were subthemes of 'Preparedness and Readiness' and 'Acceptance and Adaptation' (Figure 4.3).

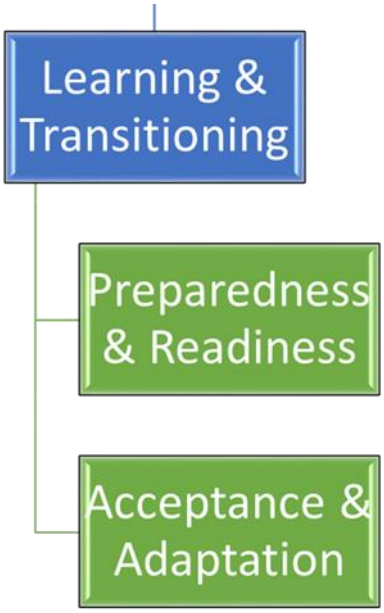

Figure 4.3 Learning and Transitioning

Preparedness and Readiness

Throughout the interviews, participants spoke about their levels of readiness to transition into their role of compound carer. These levels varied from carer to

carer. One participant mentioned, 'I was thrown in at the deep end' [Compound Carer 14]. This same participant went on to explain how transitioning to a compound caregiving situation had been very different to being a carer for a sole care-recipient:

> I know no better but I don't mind doing it you know what I mean, I really don't mind doing it. Thankfully I have the help to do it, with my mother [with dementia] gone into the home now.… dealing with one person I find easier than two … I'm not under the same pressure that I was under … I was under horrendous pressure, really I had to be there every day, I couldn't afford to get sick and I remember one day the engine went in my car the year before last and I had to get buses in or depend on people for lifts.
>
> [Compound Carer 14]

Another parental carer described how she drew from her previous experiences of caregiving for her first son with intellectual disability and cerebral palsy, which prepared her for her compound caregiving role for a second son with Asperger's syndrome:

> You know having had son number one [with ID] for 30 something years, I'm well prepared because you really do learn on the hoof. If you know nothing at the start, my god a few years in you are on the ball, I tell you … because of having son number one for so many years, when son number two came along … it all sort of worked out really well.
>
> [Compound Carer 3]

When participants were not able to draw from their own previous caring experiences, they garnered information from other family members and carers. One sibling carer described his transition to compound caring, when he took on caring responsibilities for two adult siblings, one with intellectual disability and the other with schizophrenia, after his mother passed away:

> It took a bit of time, it took a few months to get used to the whole [situation] ... After about 4 months, I really appreciated what my mum used to do … Because she had [been caring] 24/7 … And she had it for all of our lives … In the early days when I took over, and I suppose everybody was still grieving for the death of my mother, it could get a bit heated … [but] you eventually find things that work.
>
> [Compound Carer 13]

Another sibling carer shared her experience of becoming a compound carer for her brother with intellectual disability and mother with dementia. While before she had regularly spent time with them, she acknowledged that now she was less familiar with their caring needs, and spoke about the impact of having to learn this new compound caring role:

> It was very hard. I found it was mentally draining. I used to go and visit them [both care-recipients] but I did not know them that way, the care they need …

> because they were my mother [with dementia] and my brother [with ID], but I had been gone from that situation for maybe 15 years.
>
> [Compound Carer 14]

A sandwich carer for her daughter with intellectual disability, who had recently begun providing additional care to her ageing mother with a chronic illness, highlighted how her relationship with her mother influenced her readiness to transition to this compound caring situation:

> Me and mum have always been close ... you know there are days when I get tired but I'm just so happy and so thankful that I'm able to do it for her. Because even when [daughter with ID] was little she [mum] was such a great help with [her] you know, and at nights … in another job when I worked nights you know and [husband] was working different hours and [daughter with ID], she'd stay down with my mum and dad, and my dad passed away now, but you know she was great with [my daughter with ID] and they were always really close and I'm just so thankful that I'm able to do this for her now.
>
> [Compound Carer 10]

Acceptance and Adaptation

Participants spoke about the need to accept and adapt to their compound caregiving situation. Carers' propensities and abilities either enabled or inhibited smooth transitioning to occur. For example, the availability of appropriate supports, as well as the duration and permanency of compound caring circumstances was demonstrated to influence carers' ability to adapt.

One parental carer recognised the necessity to be able to adapt across different life stages. As his two sons with intellectual disability and autism transitioned through adolescence, he reflected on how their caring needs have already changed and will continue to change:

> [Caregiving] is a very fluid situation and you just have to adapt to it … Gradually, we've kind of fallen into a pattern which probably will be our future to try and maintain that and improve on that … and even now I wouldn't call me an expert at it because they're [two sons with ID] changing as well. They're growing up, they're having a lot of the same issues that any teenager would have … There's no template for this. It really is an evolving situation on numerous fronts all the time and we have to handle it.
>
> [Compound Carer 2]

A common thread that ran throughout the majority of the interviews, and which related to the carers' acceptance and adaptation, was the emphasis on self-reliance and 'just getting on with things'. In most circumstances, this was a way for carers to cope in their compound caregiving situation. This is illustrated by the following extract from an interview with a parental compound carer of three children with intellectual and developmental disabilities:

> While waiting for the services and everything else, we as parents have to just do our best, look up [things on] the internet, what's the best way to deal with this, that and everything else because it's the only way you can find the answers.
>
> [Compound Carer 4]

Other participants demonstrated a desire to just 'get on' with things. One parental carer for her son with intellectual disability described her experience transitioning to becoming a compound carer, after a recent incident had left her husband requiring additional care and assistance. She reflected on her family's life before this change as a way of framing her current perspective and acceptance of their present circumstances:

> Let's say until this happened we had a good life, we travelled a lot and you know this is just where we're at, at the moment … I just think if I'm resentful it wouldn't be good for any of us … You know it wouldn't be good for the family as a whole if I was resenting what I had to do … we are a family so we just have to get on with it.
>
> [Compound Carer 6]

This same carer went on to explain that her family was supportive, if she needed them, but she preferred to get on with the caregiving herself:

> My parents and my brothers they're all very good to me and they'll help out every now and again. Only when I ask for help, I don't ask for help too often, I just do it myself.
>
> [Compound Carer 4]

The importance of adapting and transitioning to compound caregiving as a cohesive family system was also demonstrated in other participant accounts. One compound carer described the effect of having open and honest family communication as they readily transitioned to accept their caring responsibilities for their two adult siblings with intellectual disability after their mother, the primary carer, suffered a stroke and needed institutionalised care.

> We've been there for the mother and father all our lives … nothing has changed … it's an open book at home, anything that's spoken about at home is spoken openly, we don't hide anything, and for what it's worth I think it's the way that every family should be … We put the effort into [providing care] alright. Like it didn't happen overnight you know, we [siblings] talk everything out … If something has to be said we discuss it among ourselves … and if we don't agree we say what we think and we chat it out. And so far so good, everything is going according to plan anyway.
>
> [Compound Carer 12]

While participants' accounts emphasized the need to 'just get on with things' themselves, the importance of having support services available was also noted, which provided comfort to the carers and aided their ability and propensity to adapt throughout transitioning phases of caring. A sibling carer looking after her brother

with intellectual disability and depression explained that knowing that she had access to formal medical supports was reassuring, but she still had to learn to be self-reliant and draw on her own resources:

> You learn that no matter what hits you, you have to get up in the morning. And I say, right whatever is going to hit me today I'll deal with it. I deal with it and if I can't deal with it, then I know there's a doctor at hand to talk to them [care-recipients] … There's always someone there to talk to … so I just deal with it myself, like 98% of the time I do anyway.
>
> [Compound Carer 11]

Some compound carers spoke about their difficulty with adapting to compound caring, especially in the face of social expectations. One parental carer explained how social pressures shaped the acceptance of her own caregiving circumstances and ability to engage in social situations:

> [Being a compound carer has] kind of made me hide away from people because I don't want them asking questions and stuff. I used to love meeting people before and when the kids were diagnosed with different things I was kind of hiding away and not answering questions. But I suppose as they get older and they achieve more I'm kind of coming out of myself a bit more and I'm not hiding as much anymore.
>
> [Compound Carer 4]

Carers' accounts demonstrated how the duration and permanency of compound caring circumstances could also influence carers' propensity to learn and adapt. A compound parental carer for eight years shared his own perspective on this process of adaptation:

> It's been a rocky road in terms of the stresses that [caring] causes because particularly in the early days when the two of them were small, both autistic and both volatile, I suppose but it was difficult but I think over the years we've struck a pretty good balance in terms of how we make things work and that helps.
>
> [Compound Carer 2]

4.5 Maintaining and Sustaining Continuity of Care

The third theme 'Maintaining and Sustaining Continuity of Care' describes the outcomes of the compound caring circumstances, applying carers' strategies for maintenance and balance of continued care. The theme is broken down into the following two subthemes: 'Insular Approaches to Care' and 'Refuge Outside of Caring'.

Within these dynamic and compound caring circumstances, carers expressed a desire for stability and continuity both within their immediate caring circles and close-knit family systems. Carers described several ways of enabling continuity and gave

examples such as seeking sanctuary for themselves outside of caring. These caring outcomes were developed by carers in response to their compound caring circumstances (Figure 4.4).

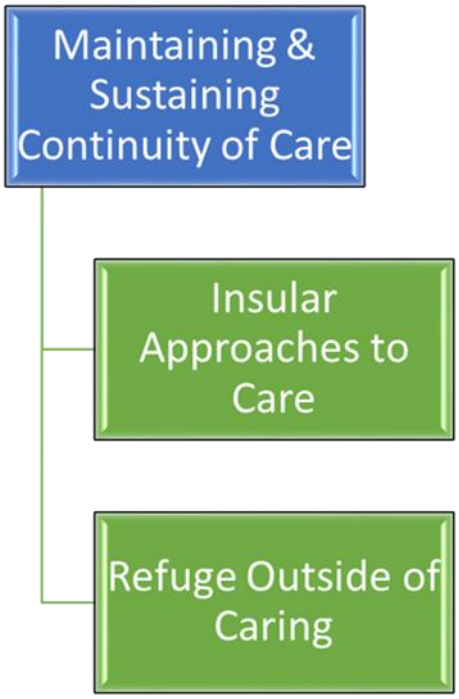

Figure 4.4 Maintaining and Sustaining Continuity of Care

Insular Approaches to Care[201]

Analysis of the interview data highlighted protective mechanisms and strategies that carers employed to maintain control over their compound caring circumstances and sustain aspects of continuity for care-recipients and their families. Participants' accounts emphasised an insular approach to care that focussed on the care-recipients, in terms of their happiness, health, and well-being. Such an approach was defined by carers as having developed an established and preferred way of caring, in which carers felt they were able to contain and control their caring circumstances independently. Many carers referred to adopting insular approaches to care with the aim of protecting the care-recipients and their routines and structures. Sometimes this was out of necessity, as often the care-recipients did not respond well to external formal supports or did not appreciate disruption to their daily routines. For example, the following sibling carer preferred to provide care himself, rather than change the current care structures:

[201] The authors of this report coined the term 'insular' to refer to the established routines and patterns of care within the home. Participants indicated that this insular approach to care allowed them to manage their caring circumstances, ensuring that routine care could continue, and described it as the best approach for the care of their relative.

> There are professionals out there and they're probably 1000 times better at the job than I am, I'm not saying [otherwise], but I wouldn't [want] to upset my brother and sister [with ID]. They're happy with the way things are at home and I wouldn't change it for the world … I don't need any help, I've been offered help and I'm more than grateful for all that.
>
> [Compound Carer 12]

This same compound carer was aware that maintaining routine care for the care-recipients was essential for their wellbeing and therefore was willing to provide care within the confines of his own home. Despite this approach, this participant knew that there was always help available should he need it at the other end of the phone:

> Anytime I want to I can pick up the phone and I have my doctor to talk to … he's a family friend as well as anything else and I don't talk to him as a doctor, I just talk to him as a friend which is also a big help. Anybody that rings me, it's great for people to ring you up and ask you how are things going because you know there are a lot of things that I don't know, so it's great when someone would ring you up and advise you about things.
>
> [Compound Carer 12]

Carers spoke about providing care in a way that protected care-recipients and their supports within an established caregiving structure and existing family system. One parental carer of two sons with intellectual disability and autism described how it took them a long time to set up, what he considered to be, the best care structures for them. The participant explained how he and his family arrived at the decision to end home-based respite because it was too 'intrusive' for their family:

> We're entitled to about 17 hours [of respite care] I think, but gradually we just petered it out. We thought it was more stressful than helpful … we're very protective, is [one] way of putting it. We sort of feel like it's taken us so long to get it even partially right, in terms of our care, we sort of feel that we're probably the only ones who can do it the way it needs to be done. And that probably isn't being sentimental or over protective, it probably is accurate. Our boys are pretty stress free in the home life, and they're happy in it, and that hasn't happened by accident, it's been a long haul with a lot of mistakes along the way. Not letting them get into stressful situations and just judging when things are going right and wrong, and it's probably just is the way it has to be to be honest with you.
>
> [Compound Carer 2]

Carers frequently expressed their concern for the potential impact that new and unfamiliar supports and services might have on the care-recipients and their well-established home care systems. After caring for his adult daughter with intellectual disability for her entire life, and now four years compound caring for his mother post-stoke with a chronic illness, the following participant highlighted the importance of the invaluable knowledge and specialist expertise that one acquires over the years in order to maintain a continuity of care for the care-recipients and family members:

> You know when you have somebody that you have spent 30 odd years of your life with and all of a sudden something comes up, you can't just … it's not everybody [that] is going to know how to handle that person, how to deal with them, to deal with their ways, the way they think, the way they act. It's a bit like … I don't know how you would describe it, but it's not like you know how to deal with that, you can't just take a person and leave them somewhere for a week … Because the effects of that psychologically alone on that person is going to take them weeks and months to recover from, because you have a system in place and you have a way of dealing with it.
>
> [Compound Carer 9]

Refuge Outside of Caring

All carers shared their experiences of having something, somewhere, or someone that provided them with an 'outlet' or 'refuge', away from the realities and demands of compound caring. This 'temporary escape' enabled them to continue in their compound caregiving role. One participant spoke about her job and how it was a break for her that she enjoyed, altogether separate from compound caring for her son with intellectual disability and her mother-in-law with dementia:

> I work 10 hours, I have a job now, every single week like. I work 2 hours every morning, it's a secretarial job. It's nothing to do with caring, it's completely different. It's what I should be doing if you know what I mean. It's my thing like it's my own job like … Oh yes if I had to be at home all the time I wouldn't be able to do it [provide care], I wouldn't. I'd have one of them killed, one or the other, I won't say which.
>
> [Compound Carer 7]

Carers identified other unique places of sanctuary. One parental carer for a son with intellectual disability, as well as a mother with mild cognitive impairment, spoke about finding peace in solitary places, taking them away from the demands of caring responsibilities:

> I go to the graveyard quite a lot too because I find it peaceful. I just like it, I've nobody telling me what to do or that kind of thing. It's grand to get out to a graveyard where you don't know anybody and you can just sit down and just have a bit of peace. That's all I need.
>
> [Compound Carer 8]

Another compound carer who cared for her son with intellectual disability and her husband with chronic illness and physical disability, having recently become more 'confined' to their home, indicated that she enjoys having time to herself and could only dream of getting some physical time away from her caregiving situation:

> Sometimes I'd just like 'me' time, when I have nobody looking for me, like I joke that my idea of heaven would be a night away in a hotel with a good book and a glass of wine, and nobody calls me, and nobody asks me for anything.

[Compound Carer 10]

One parental carer described how she sought comfort in the peer support from other families and parental carers who were in similar situations and caring for a child with intellectual disability:

> Well I met a few [parents of children with ID] there when the kids were involved with [service provider] and occupational therapists and stuff, and we kind of kept in touch and we talk about the way the services help the kids and what we do ourselves to try and help the kids. And it just went on from there really … so it usually comes down to talking about kids and is there anything wrong and then they'd offer their advice, you'd offer your advice, and you'd just be talking, and it's just good to get it out in the open sometimes.
>
> [Compound Carer 4]

4.6 Summary

In this phase of the study, a total of 14 telephone interviews were conducted with compound carers. All participants received a Carer's Allowance for the care of a person with intellectual disability, and also provided regular unpaid help to at least one other person requiring full-time care and attention. Participants ranged from 38 to 65 years in age, and had been compound caring for between 1 to 14 years. Ten participants were female carers and four were male carers. The participants were grouped into the following three distinct carer categories: the 'Parental Compound Carer'; the 'Sandwich Compound Carer'; and the 'Sibling Compound Carer'. Findings were presented under three main themes and six subthemes. The first theme, 'Divisions of Compound Caring', situated carers within their compound caring roles. Examples of the approaches adopted by participants included segregating and embracing roles and responsibilities; the two subthemes were 'Compartmentalisation' and 'Embodiment of Care'. The second theme, 'Learning and Transitioning', outlined the processes inherent in learning and adapting to the compound caregiving situation. This theme had the following two subthemes: 'Preparedness and Readiness' and 'Acceptance and Adaptation'. The final theme, 'Maintaining and Sustaining Continuity of Care' described the mechanisms adopted by participants to ensure continuity of care for their care-recipient(s). The two subthemes presented under this theme were 'Insular Approaches to Care' and 'Refuge Outside of Caring'.

Chapter 5: Discussion and Conclusion

5.1 Introduction

With changing ageing trends and family structures, it is likely that the provision of family care will receive increased attention over the coming years. In Ireland, the majority of individuals with an intellectual disability live at home with their families.[202] An unprecedented longer life expectancy among people with intellectual disability means that families are providing care for longer, and in certain cases, may either become two generation elderly families, or a person with intellectual disability may outlive their parental carer.[203] A greater understanding of family caregiving where there is a person(s) with intellectual disability can help to inform policies and services, which can then be better placed to provide appropriate and suitable supports to meet the needs of people with intellectual disability and their families.[204]

The overall aim of this study was to explore family carers' experiences of caring for a person with intellectual disability. The study was comprised of two phases. The first phase consisted of an anonymous postal survey of 600 family carers in receipt of a welfare payment for the care of a person with intellectual disability, aged 16 years and older. A total of 247 questionnaires were completed and returned, yielding a 41% response rate. This participation rate is considered reasonable when compared to other survey studies.[205] A noted limitation of the study is that the findings cannot be generalised to all family carers of people with intellectual disability. The study presents findings from 'a subgroup' of family carers, and those who do not qualify for a Carer's Allowance, or are in receipt of Carer's Benefit or who are in full-time employment are not represented.

The second phase of the study consisted of 14 in-depth telephone interviews with compound carers; these family carers provided regular unpaid care to another person requiring full-time care, in addition to a person with intellectual disability. This chapter will present the main findings of the study in the context of relevant Irish and international literature. In addition, the implications for practice, policy, and research will be outlined, along with the limitations of the study.

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[202] Linehan, C., O'Doherty, S., Tatlow-Golden, M., Craig, S., Kerr, M., Lynch, C., *et al.* (2014). **Mapping the National Disability Policy Landscape.** Dublin: School of Social Work and Social Policy, Trinity College.

[203] McCallion, P., McCarron, M. and Force, L.T. (2005) A measure of subjective burden for dementia care: The caregiving difficulty scale- Intellectual Disability. **Journal of Intellectual Disability Research,** 49 (5), 365–371.

[204] Chadwick, D.D., Manna, H., Iriarte, E.G., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A. and Harrington, G. (2013) Family voices: Life for family carers of people with intellectual disabilities in Ireland. **Journal of Applied Research in Intellectual Disabilities,** 36, 119–132.

[205] McConnell, D., Savage, A. and Breitkreuz R. (2014) Resilience in families raising children with disabilities and behaviours problems. **Research in Developmental Disabilities**, 35, 833–848.

5.2 Profile of Carers

The profile of family carers reported in this study closely matched that of all carers in receipt of a Carer's Allowance for the care of a person with intellectual disability, aged 16 years and older. In this study, over 81.1% of respondents were female, compared to 84.4% of total carers registered on the DSP database, who are in receipt of a Carer's Allowance and providing care to a person with intellectual disability aged 16 years and older.[206] These figures are higher than those from national census data which suggest that 61.2% of carers (who are aged 15 years and older) are female.[207] However the census data relates to all carers, not just carers of people with intellectual disabilities. The study findings also indicated that just 5.9% of respondents had a third level education (degree or higher). This figure is substantially lower than the national average, which suggests that 31% of individuals aged 15 years and older have a third level qualification.[208] Lower levels of educational attainment might be attributed to the less time available to carers outside their caregiving role and responsibilities.

There has been a marked increase in the number of lone carers for people with intellectual disabilities over the last decade in Ireland.[209] Over a third of respondents indicated that they were unmarried or without a partner (i.e. single, separated, divorced or widowed). Barron and colleagues (2006) also observed that almost a third of individuals with intellectual disabilities living in the community in Ireland were living with a lone parent. Kelly et al. (2009) stated that this is a reality for many families and support services need to acknowledge this if family needs are to be adequately addressed.

The survey in the first phase of the study found that the majority of respondents were a parental carer of a person with intellectual disability and just over one in ten was a sibling carer. As people with intellectual disability are now living longer, an increasing number are beginning to outlive their parents, and it is likely that the proportion of sibling carers will increase.[210] Recent findings from the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA) reported that over two thirds of carers of people with intellectual disability aged 50

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[206] Department of Social Protection Personal Communication, November 2015

[207] Central Statistics Office (CSO) (2012a) **Profile 8. Our Bill of health**. Dublin: The Stationary Office.

[208] Central Statistics Office (CSO) (2012b) **Profile 9. What we know**. Dublin: The Stationary Office.

[209] Kelly F., Craig S., McConkey R. and Mannan H. (2009) Lone parent carers of people with intellectual disabilities in the Republic of Ireland. **British Journal of Learning Disabilities**, 37, 265–270.

[210] Brennan, D., Murphy, R., McCallion, P., Griffiths, M. and McCarron, M. (2016) **Understanding family strategies that enable long term and sustainable home environments for older people with intellectual disability. Executive Summary.** Dublin: Trinity College Dublin.

years and older are sibling carers.[211] However, Bittles and colleagues (2002) warn that as women are having fewer children today, the number of siblings to look after a brother or sister with an intellectual disability will diminish and this traditional informal source of support may not be as available in years to come. A smaller Irish study funded by the National Disability Authority involving focus groups and interviews with 17 family carers of people with intellectual disability, found that sibling carers in particular, struggled with providing care, and reported feeling physically and mentally restricted as primary carers.[212] There is also evidence in the literature to suggest that sisters tend to provide more support to people with intellectual disability than brothers.[213,214] Consistent with this evidence, the current study found that twice as many sisters were the primary carer to their sibling with intellectual disability than brothers.

5.3 Caregiving Activities

Almost three quarters of carers indicated that they provided care for more than 100 hours a week, implying that they provided care for 24 hours a day, seven days a week. This rate of care is much higher than that indicated by census data on carers.[215] However, this may be reflective of the high proportion of parental carers in the current study, as well as the criteria that needs to be met in order to qualify for a Carer's Allowance; that is care-recipients must require full-time care and attention.

The literature suggests that working outside of the home can have several benefits for carers' health and informal social connections.[216] Recipients of the Carer's Allowance are permitted to work and/or study outside of the home for up to 15 hours a week. Despite the many benefits, just one fifth of respondents engaged in work for up to 15 hours a week, with just one respondent indicating that they worked and studied outside of the home. Family carers often have limited time available to engage in employment which can often result in carers being socially

[211] IDS-TILDA (2016) IDS-TILDA Valuing carers' involvement. Accessed on 20 June from: http://www.idstilda.tcd.ie/info/

[212] Brennan, D., Murphy, R., McCallion, P., Griffiths, M. and McCarron, M. (2016) **Understanding family strategies that enable long term and sustainable home environments for older people with intellectual disability. Executive Summary.** Dublin: Trinity College Dublin.

[213] Orsmond, G., and Seltzer, M. (2000) Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. **American Journal on Mental Retardation**, 105, 486–508.

[214] Coyle, C., Kramer, J., and Mutchler, J.E. (2014) Aging together: Sibling carers of adults with intellectual and developmental disabilities. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (4), 302–312.

[215] Central Statistics Office (CSO) (2012a) **Profile 8. Our Bill of health**. Dublin: The Stationary Office.

[216] Rozario, P.A., Morrow-Howell, N. and Hinterlong, J.E. (2004) Role enhancement or role strain. Assessing the impact of multiple productive roles on older caregiver well-being. **Research in Aging**, 26 (4), 413–418.

isolated.[217] In fact, those who assume caregiving responsibilities are likely to reduce their hours to part-time or leave employment altogether.[218] While survey data were not collected on carers' pre-caregiving employment status in this study, it is likely that many carers may have given up work to become full-time carers. Studies have shown that employment retention increases when carers have access to flexible working hours, unpaid family leave, and paid days off.[218] This highlights the importance of employers creating supportive working environments, offering flexible working arrangements to family carers in employment and negotiating work hours, leave, and days off for care work.

5.4 Carers' Health and Wellbeing

This study collected information on respondents' health and wellbeing. Overall, respondents' self-reported health was poorer when compared to national data on carers. Two thirds of respondents reported that their own general health was good, very good, or excellent, while the 2011 census showed that 84.8% of carers rated their health as either good or very good.[219] This figure relates to all carers including younger carers, which may explain the higher levels of self-reported good health.

Approximately two in five respondents scored above the threshold on the General Health Questionnaire 12 (GHQ12) for psychological distress and respondents were significantly more likely to be female carers. This finding is consistent with other studies which have also found high levels of psychological distress among family carers of people with intellectual and developmental disabilities.[220,221] The proportion of carers reporting high levels of psychological distress is substantially higher than the national prevalence of psychological distress, which was reported at 12%.[222] Similarly, Tedstone Doherty and colleagues (2008) found that women had proportionally higher levels of psychological distress than men. Other national studies have also found higher rates of psychological distress among carers than in the general

[217] Shearn, J., and Todd, S. (2000) Maternal employment and family responsibilities: The perspectives of mothers of children with intellectual disabilities. **Journal of Applied Research in Intellectual Disabilities**, 13, 109–131.

[218] Pavalko, E.K. and Henderson, K.A. (2006) Combining care work and paid work: Do workplace policies make a difference? **Research on Aging,** 28 (3), 359–374.

[219] Central Statistics Office (CSO) (2012a) **Profile 8. Our Bill of health**. Dublin: The Stationary Office.

[220] Ekas, N. and Whitman, T.L. (2010) Autism symptom topography and maternal socioemotional functioning. AJIDD: **American Journal of Intellectual and Developmental Disabilities**, 115 (3), 234–249.

[221] Dawson, F., Shanahan, S., Fitzsimons, E., O'Malley, G., Mac Giollabhui, N., and Bramham J. (2016) The impact of caring for an adult with intellectual disability and psychiatric comorbidity on care stress and psychological distress. **Journal of Intellectual Disability Research**, 60 (6), 553–563.

[222] Tedstone Doherty, D., Moran, R. and Kartalova-O'Doherty, Y. (2008) **Psychological distress, mental health problems and use of health services in Ireland. HRB Research Series 5**. Dublin: Health Research Board.

public.[223] As such, it has been recommended that practitioners should prospectively identify carers and intervene before carers' psychological distress is already present.[224]

Lee, Draper and Lee (2001) noted that people with low connectedness have difficulty with being appropriately assertive and sociable and have a tendency to remain guarded and engage in social avoidance, preventing other people from getting too close. Individuals in this group are quite hesitant to enter into social situations and are concerned with how other people view them. The present study found that the majority of respondents scored high in social connectedness. Carers generally experienced a strong sense of belonging and feelings of being connected to their friends and family members around them and to others in society. However over a quarter of respondents scored low in social connectedness and compound carers were significantly more likely to be less socially connected than non-compound carers. This finding is consistent with the subtheme 'insular approaches to care' (main theme 'maintaining and sustaining continuity of care'), which emerged from the qualitative data gathered from compound carers in phase 2 of the study. Carers portrayed themselves as self-reliant with an established way of caring in which they adopted strategies that helped them to maintain everyday routines for their care-recipients. This approach was often taken in the absence of, or preference over, support from others. Perhaps carers chose to remain disconnected or adopted such insular approaches in order to cope with their multiple caregiving roles and to protect their systems of home care against stigma and the negative attitudes, which are sometimes experienced from others.[225,226] Parents of children with intellectual disability may find it more difficult to manage public perceptions of their child and their family, and to sustain the perception of 'normalcy' and therefore may struggle to maintain positive social relationships.[227,228]

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[223] Drennan, J., Lafferty, A., Treacy, M.P., Fealy, G., Phelan, A., Lyons, I. and Fox, P. (2012) **Older people in residential care settings: Results of a national survey of staff-resident interactions and conflicts.** Dublin: NCPOP, University College Dublin.

[224] Cherry, M.G., Salmon, P., Dickson, J.M, Powell, D., Sikdar, S. and Ablett, J. (2013) Factors influencing the resilience of carers of individuals with dementia. **Reviews in Clinical Gerontology**, 23, 251 –266.

[225] Blacher, J., and Hatton, C. (2009) Families in context: Influences on coping and adaptation. In S.L. Odom, R.H. Horner, M.E. Snell, and J. Blacher (Eds.), Handbook of developmental disabilities (pp. 531– 551). New York, NY: Guilford Press.

[226] Mak, W.W.S. and Cheung, R.Y.M. (2008) Affiliate stigma among caregivers of people with intellectual disability or mental illness. **Journal of Applied Research in Intellectual Disabilities**, 21, 532–545.

[227] Bromley, J., Hare, D.J., Davison, K. and Emerson, E. (2004) Mothers supporting children with autistic spectrum disorders social support, mental health status and satisfaction with services. **Autism**, 8 (4), 409–423.

[228] Smith, L.E., Greenberg, J.S., Seltzer, M.M. (2012) Social support and well-being at mid-life among mothers of adolescents and adults with autism spectrum disorders. **Journal of Autism and Developmental Disorders**, 42 (9), 1818–1826.

5.5 Profile of Care-recipients

The profile of care-recipients with intellectual disability reported in this study closely matched that of data supplied by the DSP on care-recipients with intellectual disability aged 16 years and older. In this study, the proportion of care-recipients that were male (71.1%) was similar to the proportion reported by the DSP (68.6%).[229] It is worth noting that these proportions are much higher than the proportion of males with intellectual disability (58.2%) that are registered on the National Intellectual Disability Database (NIDD).[230]

Care-recipients had mainly mild to moderate levels of intellectual disability and there were no significant differences in severity of intellectual disability between male and female care-recipients. This reflects the data available on intellectual disability from the NIDD.[230] Other Irish research studies have reported that there is a greater proportion of family carers providing care at home for a person with severe intellectual disability, than a mild intellectual disability.[231] This discrepancy may be attributable to the differences in carer samples. Carers in this study were recipients of a Carer's Allowance and may not have been registered on the NIDD. Barron and colleagues (2006) implied that, within the Republic of Ireland, individuals with severe disabilities are more apt to be moved into out-of-home residential accommodation. In the present study, care-recipients had relatively low levels of challenging behaviour and male care-recipients were more likely to exhibit these behaviours than female care-recipients.

5.6 Family Resilience

A focus on maximising and sustaining resilience among family carers can help to ensure that family caregiving can continue to be a valuable source of care provision for people with intellectual disability. Interventions aimed at enhancing resilience among parents of children with intellectual disability may not only benefit mothers and fathers, but may also benefit the child with intellectual disability.[232]

[229] DSP Personal Communication (2015)

[230] Kelly, C. (2015) **HRB Statistics Series 28 Annual report of the National Intellectual Disability Database committee 2014.** Dublin, Ireland: Health Research Board.

[231] Barron, S., McConkey, R. and Mulvany, F. (2006) Family carers of adult persons with intellectual disabilities on the Island of Ireland. **Journal of Policy and Practice in Intellectual Disabilities,** 3 (2), 87–94.

[232] Bekhet, A.K., Johnson, N.L. and Zauszniewski, J.A. (2012) Resilience in family members of persons with autism spectrum disorder: a review of the literature. **Issues in Mental Health Nursing**, 33 (10), 650–656.

Research studies have reported lower levels of resilience among parents of children with intellectual disability than in the general population.[233,234,235] The findings from the present study imply that the family carers who participated in the survey were relatively resilient. This may be attributable to a number of factors, including the fact that the majority of respondents had good self-reported health and high levels of social connectedness. Similar propensities have been highlighted by other studies of family carers for people with intellectual disability and show that carers adjust to circumstances overtime through the acquisition of new skills and enabled coping mechanisms.[236] This finding is consistent with the theme 'learning and transitioning', which emerged from the qualitative data gathered from compound carers in phase 2 of the study.

A number of factors were identified in this study that were associated with low carer resilience and may be considered risk factors. These include being a compound carer, living with the care-recipient with intellectual disability, having high levels of psychological distress, poor/fair self-reported general health, having low levels of social connectedness, experiencing high levels of challenging behaviours from the care-recipient, and having low levels of support from formal and informal supports.

According to a literature review on resilience conducted by Bekhet and colleagues (2012), promoting and strengthening the resilience protective factors of parents of children with autism spectrum disorder helps them to better manage their stresses. For example, volunteering may be one means of enhancing resilience in families of people with intellectual disabilities.[235] Similarly, Thompson et al. (2014) found that resilience was related to the closeness of a family unit and altruistic behaviour adopted within the family. According to Grant and Whittell (2000), perceptions of family cohesion and upbringing are also shown to positively contribute to a family's readiness to provide care. This finding is consistent with the subtheme 'preparedness and readiness', which emerged from the qualitative data gathered from compound carers in phase 2 of the study.

[233] Baxter, C., Cummins, R.A. and Yiolitis, L. (2000) Parental stress attributed to family members with and without disability: A longitudinal study. **Journal of Intellectual and Developmental Disability**, 25, 105–118.

[234] Baker, L.B., Blacher, J. and Olsson, M.B. (2005) Preschool children with and without developmental delay: Behaviour problems, parents' optimism and wellbeing. **Journal of Intellectual Disability Research**, 49, 575–590.

[235] Wong, P.K.S. and Lam, T.L. (2015) Enhancing the resilience of parents of adults with intellectual disabilities through volunteering: An exploratory study. **Journal of Policy and Practice in Intellectual Disabilities,** 12 (1), 20–26.

[236] Chadwick, D.D., Manna, H., Iriarte, E.G., McConkey, R., O'Brien, P., Finlay, F., Lawlor, A. and Harrington, G. (2013) Family voices: Life for family carers of people with intellectual disabilities in Ireland. **Journal of Applied Research in Intellectual Disabilities,** 36, 119–132.

Carers' sense of control in their caring circumstances may enable them to maintain resilience and to positively adapt to the challenges associated with caregiving.[237,238] A study that developed a psychosocial model of resilience in families caring for a person with intellectual disability, also discussed the assertion of control as a way for carers to bring order into their situation, highlighting methods of structure and routine, as well as acquiring new skills and positive perspectives.[239]

According to Wong and Lam (2015), enhancing the protective factors of a person can empower them and give them a greater degree of strength and resilience. Furthermore, resilience indicators are critical for informing appropriate professional support and effective service provision for families.[240,241]

5.7 Availability of Appropriate Services and Supports

Respondents in this study indicated that they availed of a range of services. However those who indicated that they required certain services did not always receive them. For example, just over half of the respondents who reported that they required crisis respite care in the preceding six months did not receive the service. Similarly, half of the respondents who required a home-based respite service did not receive the service. McConkey and colleagues (2010) reported that there was a notable increase in the number of families requiring respite care and, due to additional funding available from government sources, there was a discernible rise in the number of people receiving respite breaks. There were marked inequalities in the availability of the services across Ireland. Kelly (2015) noted that, despite an increase in provision of crisis and planned respite services in the last two decades, there was a marked decline in provision in more recent years.

More than one in five respondents indicated that they required alternative therapies (e.g. sensory therapy) for their care-recipient in the previous six months, however, the majority of respondents reported that they did not receive this service. In addition, of those who reported requiring psychological/counselling services, over a third indicated that they did not receive the service. There were also unmet needs in dietician services, home-based respite services, and occupational therapy. According

[237] Grant, G., Ramcharan, P. and Goward P. (2003) Resilience, family care, and people with intellectual disabilities. **International Review of Research in Mental Retardation**, 26, 135–173.

[238] Windle, G. (2011) What is resilience? **Reviews in Clinical Gerontology**, 21, 152– 169.

[239] Grant, G., Ramcharan, P. and Flynn, M. (2007) Resilience in families with children and adult members with intellectual disabilities: Tracing elements of a psycho-social model. **Journal of Applied Research in Intellectual**, 20 (6), 563–575.

[240] Ouellette-Kuntz, H., Blinkhorn, A., Rouette, J., Blinkhorn, M., Lunsky, Y. and Weiss, J. (2014) Family resilience: An important indicator when planning services for adults with intellectual and developmental disabilities. **Journal on Developmental Disabilities**, 20 (2), 55–66.

[241] Thompson, R., Linehan, C., Glynn, M. and Kerr, M.P. (2013) A qualitative study of carers' and professionals' views on the management of people with intellectual disability and epilepsy: A neglected population. **Epilepsy and Behavior**, 28 (3), 379–385.

to Kelly (2015), there is a significant demand for new and enhanced multidisciplinary support services for a person with intellectual disability and their families in Ireland. According to figures from the NIDD, just less than three quarters of those registered on the database require a new or enhanced multidisciplinary support service for the period of 2015 to 2019. In particular, there is substantial demand for the therapeutic inputs, including psychology, occupational, and speech and language therapies.[242] This increased demand may go some way towards explaining why some families may not have received the services they required, and instead may have been placed on a waiting list. Families' frustration and disappointment in relation to accessing information and available services, as well as the coordination of care provision across sectors for families caring for a person with intellectual disability in Ireland has been commonly reported in the literature.[243,244,245] In the present study, following the respondent's partner, a day centre/school/college was deemed the second most helpful source of support. Across Ireland, day centres are the most commonly available services to families and people with intellectual disability.[246]

This study found that low levels of formal supports were related to low levels of family resilience; it is therefore important to identify the gaps in supports so that these can be targeted and thus resilience in families can be enhanced. A recent Irish study comprising interviews and focus groups with a total of 17 family carers of people with intellectual disability also echoed this. The study's authors indicated that day-to-day services for people with intellectual disability, such as day services, workshops, and training centres, were 'perceived by family carers to play an integral role in maintaining family caregiving capacity'.[247] The study also pointed out that family caregiving capacity was compromised by fundamental flaws in the support system for carers, which related to inequitable eligibility criteria for Carer's Allowance and the reduced and varied availability of respite care.[247]

Hill and Rose (2009) suggested that a more holistic response is required so as to ensure that families avail of suitable supports and have access to social support

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[242] Kelly, C. (2015) **HRB Statistics Series 28 Annual report of the National Intellectual Disability Database committee 2014.** Dublin, Ireland: Health Research Board.

[243] McConkey R. (2005) Fair shares? Supporting families caring for adult persons with intellectual disabilities. **Journal of Intellectual Disability Research**, 49 (8), 600-612.

[244] Power, A. (2009) Is the system working for the system? Carers' experiences of learning disability services in Ireland. **Health and Social Care in the Community**, 17**,** 92–98.

[245] Chadwick, D.D., Finlay, F., García Iriarte, E., Greene, S., Harrington, J., Lawlor, A., Mannan, H., McConkey, R., O'Brien, P., Spain, J. and Turner, A. (2010) **Family Voices: Life in Ireland for families of people with intellectual disabilities.** Dublin: National Institute for Intellectual Disability, Trinity College Dublin.

[246] Barron, S., McConkey, R. and Mulvany, F. (2006) Family carers of adult persons with intellectual disabilities on the Island of Ireland. **Journal of Policy and Practice in Intellectual Disabilities,** 3 (2), 87–94.

[247] Brennan, D., Murphy, R., McCallion, P., Griffiths, M. and McCarron, M. (2016) **Understanding family strategies that enable long term and sustainable home environments for older people with intellectual disability. Executive Summary.** Dublin: Trinity College Dublin.

facilities such as parents groups, and implied that the most important aspect of support is how helpful it is perceived to be, rather than the amount available. The present study highlighted the importance of informal supports in maintaining family resilience, particularly as findings showed a positive correlation between family resilience and perceived helpfulness of family and other informal supports. These informal support networks are central to family cohesion where there is a person with intellectual disability.[248] In a study of 32 parents of children with intellectual disability, Heiman (2002) highlighted the importance of a range of informal social sources which found that parents drew on a combination of supports including the nuclear family, grandparents, and other relatives in order to maintain a routine. This finding is consistent with the theme 'Maintaining and sustaining continuity of care', which emerged from the qualitative data gathered from compound carers in phase 2 of the study. This will become more relevant however, as family carers grow older and become frail, their social and support networks tend to shrink, increasing their risk of becoming socially isolated.[249]

5.8 The Compound Carer

More than a quarter of respondents in this survey indicated that they were a 'compound carer'; that is, they provided regular unpaid care to another dependent person, in addition to the person with intellectual disability for whom they received a Carer's Allowance. In the majority of cases, the compound carers were also providing care to a parent/parent-in-law or a child. Findings from the postal survey found that compound carers were significantly more likely to have low levels of resilience and low levels of social connectedness, when compared to non-compound carers. Findings from the 14 compound carer interviews gave an indication of the diverse nature and unique categories of caregiving circumstances associated with compound caregiving (parental, sibling and sandwich compound carers). Similar caregiving situations have been found in the literature.[250,251,252,253]

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[248] Peer, J. W. and Hillman, S.B. (2014). Stress and resilience for parents of children with intellectual and developmental disabilities: A review of key factors and recommendations for practitioners. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (2), 92–98.

[249] Magrill, D. (2007) **Supporting older families: Making a real difference**. London: Mental Health Foundation.

[250] Grundy, E. and Henretta, J.C. (2006) Between elderly parents and adult children: A new look at the intergenerational care provided by the sandwich generation. **Ageing and Society**, 26 (5), 707–722.

[251] Tebes, J.K. and Irish, J.T. (2000) Promoting resilience among children of sandwiched generation caregiving women through caregiver mutual help. **Journal of Prevention and Intervention in the Community**, 20 (1-2), 139–158.

[252] Perkins, E.A., and Haley, W.E. (2010) Compound caregiving: When lifelong caregivers undertake additional caregiving roles. **Rehabilitation Psychology**, 55 (4), 409–417.

[253] Dew, A., Llewellyn, G., and Balandin, S. (2004) Post-parental care: A new generation of sibling-carers. **Journal of Intellectual and Developmental Disability**, 29, 176–179.

The findings presented related to the context, processes, and outcomes of the compound caregiving experience of family carers of people with intellectual disability. Data analysis revealed that in some cases, approaches to compound caregiving included the separation of caregiving roles and responsibilities, while in other cases, the role was completely integrated into the carer's life and own identity. Examples of the separation of carers' time and roles have also been found in the compound caregiving literature, particularly when having to prioritize the care.[254]

The processes of transitioning and learning described in the study included preparedness, readiness, acceptance, and adaptation. Transitioning into a new caregiving role can be difficult and demanding for any family member, not just because of having new responsibilities for their care-recipient, but also because they have to manage their new care providing role with other aspects of their life.[255] Most parental carers of a person with intellectual disability expect that another family member will assume caregiving responsibilities once they are no longer able to provide care. However these assumptions are often made without making any formal arrangements.[255,256] When a parent passes away, often siblings are expected to continue the care as before, but this is constrained to some extent by the previous structures and habits put into place by the deceased parent. For example, negotiating a group home placement for an adult with intellectual disability who has lived at home for his/her entire life is challenging and can totally disrupt their routine and social supports.[255] Furthermore, siblings tend to lack the experience and knowledge of services that their parents had and need information and support in their own right.[257]

The interview data revealed that decisions made, in relation to compound care provision, showed evidence of personal sacrifice and familial commitment. The dynamics of family solidarity and sibling relationships have been shown to impact positively on the intergenerational exchanges in caring structures of families.[258] In particular, family closeness, parenting perspective, as well as severity of intellectual disability, are factors shown to influence a sibling's decision to take up caring

[254] Kwok, H. (2006) The son also acts as major caregiver to elderly parents: A study of the sandwich generation in Hong Kong. **Current Sociology,** 54 (2), 257–272.

[255] Coyle, C., Kramer, J., and Mutchler, J.E. (2014) Aging together: Sibling carers of adults with intellectual and developmental disabilities. **Journal of Policy and Practice in Intellectual Disabilities**, 11 (4), 302–312.

[256] Tebes, J.K. and Irish, J.T. (2000) Promoting resilience among children of sandwiched generation caregiving women through caregiver mutual help. **Journal of Prevention and Intervention in the Community**, 20 (1-2), 139–158.

[257] British Institute of Learning Disabilities (BILD) (2012) **BILD Factsheet: Older people with a learning disability**. Worchester, UK: BILD.

[258] Grundy, E. and Henretta, J.C. (2006) Between elderly parents and adult children: A new look at the intergenerational care provided by the sandwich generation. **Ageing and Society**, 26 (5), 707–722.

responsibilities.[259,260] The provision of intergenerational help and care in families, between children and parents, may also be contingent on the time and resources available, the cost of missed opportunities and the health of those providing care.[261] This is further supported by broader claims that perceptions of family cohesion and upbringing seem to positively contribute to a family carer's willingness to provide care.[262] Having a secondary caregiver and other supports has been shown to reduce caregiving burden and improve quality of life for sandwich compound carers.[263]

Findings also demonstrated that compound carers' priority was to maintain continuity for the care of the care-recipients and many portrayed the approaches they adopted to ensure this could occur. Some of these were insular in nature and the carers frequently adopted a self-reliance approach to their caregiving roles and responsibilities. While it is during the compound caregiving period that stress-ameliorating interventions and supports would be most beneficial to the carer, many may not accept or seek help. Perkins (2010) stated that 'it is probable that, due to the potentially transient nature of the scenarios, and variability in their potential duration, most affected families merely try to overcome these (compound caring) circumstances as best they can, rather than reaching out for additional support' (p. 253).[264]

5.9 Implications of the Study's Findings

Implications for Policy and Practice

This study provides important information about family carers who care for a relative with intellectual disability in Ireland. The study findings suggest that while many carers manage well and adapt to their caregiving roles and responsibilities, this may be at the detriment of their own health, psychological wellbeing, identity, autonomy, and social networks. The findings highlighted the need to support carers with maintaining good mental health. Four out of ten carers scored higher than the threshold for psychological distress, which is a much higher rate than that found in

[259] Seltzer, M. M., Greenberg, J. S., Orsmond, G. I. and Lounds, J. (2005) Life course studies of siblings of individuals with developmental disabilities. **Mental Retardation**, 43 (5)**,** 354–359.

[260] Krauss, M.W., Seltzer, M.M., Gordon, R. and Friedman, D.H. (1996) Binding ties: the roles of adult siblings of persons with mental retardation. **Mental Retardation,** 34 (2), 83–93.

[261] Brandt, M., Haberkern, K. and Szydlik, M. (2009) Intergenerational help and care in Europe. **European Sociological Review**, 25 (5), 585–601.

[262] Grant, G., and Whittell, B. (2000) Differentiated coping strategies in families with children or adults with intellectual disabilities: The relevance of gender, family composition and the lifespan. **Journal of Applied Research in Intellectual Disabilities**, 13 (4), 256–75.

[263] Rubin, R.M. and White-Means, S.I. (2009) Informal caregiving: Dilemmas of sandwiched caregivers. **Journal of Family and Economic Issues**, 30 (3), 252–267.

[264] Perkins, E.A. (2010) The compound caregiver: A case study of multiple caregiving roles. **Clinical Gerontologist**, 33, 248–254.

the general population.[265] In addition, higher levels of psychological distress were associated with lower levels of resilience. Poor general health and low social connectedness were also found to be negatively associated with resilience. These findings suggest that greater efforts are needed to identify and support carers who are experiencing poor psychological wellbeing and poor general health. In addition, since this cohort of carers is more likely to find themselves struggling with adapting to caregiving, managing their caregiving responsibilities and overcoming the pressures associated with caring for their relative with intellectual disability, early engagement with services and support are needed to forestall experiences of psychological distress.

Furthermore, as more than a quarter of carers reported low social connectedness, there is a need for supportive policies that facilitate greater societal participation and integration for carers, and that promote and create opportunities for carers to develop peer and support networks and engage in activities outside of their caring roles, for example, in work and study. The qualitative data echoed the fact that these external activities also present an opportunity for carers to have some protected time for themselves and space away from caregiving.

Additional resources also need to be made available to families with relatives with intellectual disability who exhibit challenging behaviours. Since carers whose relative displayed higher levels of challenging behaviours had lower levels of resilience, education and training supports should include materials and information on supports that are available to families on behaviour management techniques. Also, health and social care professionals should work closely, not just with the family carer, but with their relative and with the family as a unit, in order to explore ways in which they can be best supported in responding to, and managing these behaviours, so that family resilience can be maintained.

The compound carer in particular warrants greater attention; one in four carers indicating that they also provided regular care to one or more other individuals, in addition to their relative with intellectual disability, and this number is likely to increase in years to come. These carers reported significantly lower levels of resilience and social connectedness. As demonstrated by the qualitative data, the circumstances of each compound caregiving situation varies widely, and therefore policies need to acknowledge and recognise that each family unit has unique circumstances and requires a multidisciplinary approach in order to meet their diverse needs.

As families continue to transition, changes to family systems and structures are inevitable. Therefore supports must also evolve to meet families' transient needs in a way that enables carers to adapt and build resilience. It was evident from the interview data that supports should be introduced early on, in a proactive manner, so

[265] Tedstone Doherty, D., Moran, R. and Kartalova-O'Doherty, Y. (2008) **Psychological distress, mental health problems and use of health services in Ireland. HRB Research Series 5**. Dublin: Health Research Board.

as to ensure smooth transitioning in the caregiving circumstances. Consequently interventions must be multifaceted to reflect the dynamic processes, and policies and service responses need to be flexible, so that they too can be tailored to adequately respond to the needs of individual family caregiving situations.

The study findings also found that gaps in formal service provision exist and therefore must be addressed. While most carers indicated that they were in receipt of the services they required, there were some notable gaps. Namely, there were unmet needs in areas such as crisis respite care, home-based respite care, alternative therapies, dietician services, and occupational services. In order for families caring for a person with intellectual disability to be supported in the best possible way, such services warrant greater allocation of resources so that people with intellectual disability and their families do not have to forgo essential supports. The processes involved in the allocation of services needs to be examined in greater detail so as to ensure that they are distributed fairly and equitably to people with intellectual disabilities and their families.

The study findings also highlighted the importance of carers' perceived helpfulness of formal supports, as well as familial and other informal supports, in maintaining family resilience. It is not enough just to be in receipt of supports from formal and informal sources, but carers have to perceive them to be helpful. Therefore, carers' satisfaction levels with services should be regularly assessed to determine whether the provision of services and supports are being utilised in the best possible way and carers feel that they are actually benefiting from them. While efforts are currently underway in Ireland to develop a Carers' Needs Assessment, at the time of reporting, this was still at development stage.[266]

More attention should also be attributed to in-home supports for carers. The interview data revealed the level of importance placed on maintaining routines and schedules for individuals with intellectual disability and providing care in a consistent manner. This meant that carers became self-reliant and adopted insular caring approaches in an effort to avert any disruptions to the care of their relative. Therefore, since carers frequently feel that they are the only person in a position to provide regular care to their relative, greater consideration should be given as how best to support carers in the home in a way that is not disruptive to their daily routine or comfort levels.

The Irish government has begun to recognise family carers and the critical role they play in providing care with the publication of the National Carers' Strategy,[267] however it is important that the strategy is now fully implemented. In addition, under the demographic pressures of an ageing society and the inevitable changing nature of family systems and caring structures, it is important that caring responsibility for

[266] Care Alliance Ireland (CAI) (2015b) **Discussion Paper 2: Intellectual Disability, Caring and Role Reversal.** Dublin: CAI.

[267] Department of Health (DoH) (2012a) **The National Carers' Strategy: Recognised, Supported, Empowered**. Dublin: The Stationary Office.

people with intellectual disability living in the community is not placed solely on family systems alone, and rather, supports need to be collaborative and developed to include the wider remit of social care, health care, and welfare systems. Furthermore, the design and development of interventions to support carers necessitates a multidisciplinary approach, paying particular attention to the family context.

Implications for Research

Further research with family carers of people with intellectual disability is warranted. Longitudinal data collected from multiple perspectives would help to identify the changing needs of families caring for a person with intellectual disability over time, especially as the carer and the person with intellectual disability ages. It would also be worth exploring other individual, social, and environmental factors that enhance resilience that have not been examined in this study. Very few studies have examined the nature of and types of compound caregiving situations within families where there a person with intellectual disabilities. Due to changing family structures and ageing profiles, the carers' role is likely to transform in the future. This means that more and more carers, including parents, siblings, and other extended family members, are likely to find themselves becoming a compound carer. Therefore this area requires further research, adopting both qualitative and quantitative research designs, to examine the compound caregiver's role and support needs.

5.10 Limitations of the Study

This study has a number of limitations which are noteworthy. The main limitation of this study is that the findings are based on data collected from carers who received a welfare payment for the full-time care of a relative with intellectual disability, and therefore the findings cannot be generalised to those carers who are in full-time employment, who do not qualify for the welfare payment, or who are in receipt of Carer's Benefit. In addition, in this study there is a reliance on carers' self-reports, and therefore the data may be subject to increased levels of response bias. For example, carers may underestimate or overestimate the frequency of challenging behaviours exhibited by their care-recipient.

5.11 Conclusion

Policies, service providers, healthcare, and social care professionals should continue to recognise the important role played by families in the provision of care for people with intellectual disability living in the community. Due to the transient nature of families, ways in which they can be best supported should be constantly evolving and explored. Particular attention should be placed on the factors that enhance family resilience, helping them to draw on and develop their strengths. In doing so, it is

necessary to recognise and respect the importance of existing family practices, routines, knowledge, and expertise. The creation of a collaborative and supportive culture that focuses on promoting resilience within families, including flexible policies as well as suitable and effective services, will ensure that family caregiving for a person with intellectual disability can continue to be sustained and valued in society.

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Appendices

Appendix I – Ethical Approval

UCD Office of Research Ethics

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27th July 2016

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RE: LS-E-15-110-Lafferty: *Exploring Resilience and Family Support Structures in Families with a Person with Intellectual Disability – Part 1*

Dear Dr Lafferty,

Thank you for your correspondence to the Human Research Ethics Committee –Sciences (27/07/16). This is to confirm that your study is exempt from full ethical review and is subject to the following conditions:

- Should the nature of your research change and thereby alter your exempt status you will need to submit an application form for review;
- You should ensure that ethical best practice is considered and applied to your research project;
- You must ensure that participants, if applicable, are aware of what is happening to them and to their data whether a study is de-identified or not;
- You have a duty of care to your participants who have the right to be informed, the right to consent to participate and the right to withdraw from the study;
- Any unexpected adverse events that occur during the conduct of your research should be notified to the Committee. Therefore you will need to submit, by email, an *Unforeseen Adverse Events Report* (HREC Doc 11);
- Please note that the granting this exemption approval is premised on the assumption that the research will be carried out within the limits of the law;
- You may require copies of submitted documentation relating to this approved application and therefore we advise that you retain copies for your own records.

.../.

Please note that your research does not require an ethical review because you have declared that you meet the exemption criteria as listed on our website:
http://www.ucd.ie/researchethics/apply/exemptions/

If you have any queries regarding the above please contact the Office of Research Ethics.

Yours sincerely,

Mr T. John O'Dowd
Chairman, Human Research Ethics Committee - Sciences

UCD Office of Research Ethics

Roebuck Castle
University College Dublin
Belfield, Dublin 4, Ireland

T +353 1 716 8767

An Oifig Eitic Thaighde UCD

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5th January 2016

Dr Attracta Lafferty
UCD School of Nursing, Midwifery and Health Systems
Health Sciences Centre
Belfield
Dublin 4

RE: LS-15-67-Lafferty: *Exploring resilience and family support structures in families with a person with intellectual disability: Part 2- The Compound Carer*

Dear Dr Lafferty,

Thank you for your responses to the Human Research Ethics Committee – Sciences (18/12/15 & 04/01/16). The Decision of the Committee is that **approval is granted** for this application which is subject to the conditions set out below.

Please note that **public liability insurance for this study has been confirmed** in accordance with our guidelines.[i]

Please note that approval is for the work and the time period specified in the above protocol and is subject to the following:

- Any amendments or requests to extend the original approved study will need to be approved by the Committee. Therefore you will need to submit by email the *Request to Amend/Extend Form* (HREC Doc 10);
- Any unexpected adverse events that occur during the conduct of your research should be notified to the Committee. Therefore you will need to Submit, by email, an *Unexpected Adverse Events Report* (HREC Doc 11);
- You or your supervisor (if applicable) are required to submit a signed *End of Study Report Form* (HREC Doc 12) to the Committee upon the completion of your study;
- This approval is granted on condition that you ensure that, in compliance with the Data Protection Acts 1988 and 2003. If applicable, all data will be destroyed in accordance

.../.

with your application and that you will confirm this in your *End of Study Report* (HREC

with your application and that you will confirm this in your *End of Study Report* (HREC Doc 12), or indicate when this will occur and how this will be communicated to the Human Research Ethics Committee;

- Please note that further **new** submissions from you may not be reviewed until any **End of Study Reports due** have been submitted to the Office of Research Ethics. That is, any earlier study that you received ethical approval for from the UCD HRECs;
- You may require copies of submitted documentation relating to this approved application and therefore we advise that you retain copies for your own records;
- Please note that the granting of this ethical approval is premised on the assumption that the research will be carried out within the limits of the law;
- Please also note that approved applications and any subsequent amendments are subject to a Research Ethics Compliance Review.

The Committee wishes you well with your research and look forward to receiving your End of Study Report. All forms are available on the website www.ucd.ie/researchethics please ensure that you submit the latest version of the relevant form. If you have any queries regarding the above please contact the Office of Research Ethics and please quote your reference in all correspondence.

Yours sincerely,

Mr T. John O'Dowd
Chairman, Human Research Ethics Committee - Sciences

[i] http://www.ucd.ie/researchethics/information_for_researchers/insurance/

Appendix 2 - Detailed Methodology

Research Design

This study adopted a mixed-methods research design combining both qualitative and quantitative methods. The first phase comprised a cross-sectional survey of family carers of people with intellectual disability aged 16 years and older, in order to examine family carers' experiences of caring for a person with intellectual disability. The second phase involved telephone interviews with compound carers to explore their experiences of providing full-time care to a person with intellectual disability in addition to having other caregiving responsibilities.

Sampling and Recruitment

Phase 1: Postal Survey of Family Carers

Facilitated by the Department of Social Protection, a postal survey was undertaken with carers who received a Carer's Allowance for the full-time care they provided to a person with intellectual disabilities. In order to be eligible for this welfare payment, a carer must be aged 18 years or older, reside in the Republic of Ireland and satisfy a means test and a habitual residence condition. The carer must also live with or in close proximity to a person with intellectual disability in need of full-time care, who does not normally live in a hospital, home or similar situation.

For the purposes of this study, it was decided to focus on family carers who were in receipt of a Carer's Allowance for care provided to a person with intellectual disabilities aged 16 years and older. According to the figures supplied by the Department of Social Protection, approximately 1,868 individuals receive the social welfare payment in respect of 1,780 care-recipients, aged 16 years and older, medically diagnosed as having autism and/or an intellectual disability (Personal Communications, Nov, 2015). A total of 600 Carer Allowance recipients were randomly selected for this survey.

Phase 2: Telephone Interviews with Compound Carers

A 'compound carer' is a person with multiple caregiving responsibilities. Compound carers who were providing care to a person with intellectual disability and also to another person were recruited to take part in a telephone interview. Carers who responded 'yes' to the following survey question (phase 1) were invited to take part in a telephone interview in phase 2 of the study: 'Apart from your relative to whom you provide full-time care, do you provide regular unpaid care to another person requiring care, due to a long-term illness, disability, frailty or other impairment (e.g. to an elderly parent, a sibling with a physical disability etc.)'. The definition of the 'compound carer' was purposely kept broad in order to account for all possible

compound caregiving situations. While a quarter of carers reported that they were in a compound caring situation in phase 1, not all compound carers wished to participate in a telephone interview. In addition, some carers were non-contactable or struggled to find the time to participate in an interview. In phase 2, a total of 14 compound carers participated in telephone interviews.

Instruments and Materials

Phase 1: Postal Survey of Family Carers

A self-completion questionnaire was developed comprising the following five sections: Carers' profile; Caregiving supports; Caregiving experience; Profile of your relative; Caregiving structures. A number of psychometric instruments were used to measure the various constructs.

Profile of Carer and Care-recipient with Intellectual Disability

Demographic profile information about the carer included gender, marital status, age, living arrangements, highest educational attainment, relationship to person with intellectual disability, number of person(s) in their household, type of Carer's Allowance, nationality and whether they lived in an urban or rural area. Carers were also asked to provide details about the care-recipient with intellectual disability, including their age, gender, severity of their intellectual disability and the frequency of challenging behaviours. In addition, respondents were asked to give details about caregiving (number of hours of care provided per week on average and length of caregiving), and the usefulness of internet-based technology to support them in their caregiving role.

Included in the questionnaire was a suite of psychometric instruments including the General Health Questionnaire (GHQ) (Goldberg and Williams 1988), Social Connected Scale-R (SCS-R) (Lee, Draper and Lee 2001), Resilience Scale for Adults (RSA) (Friborg et al. 2005), the Learning Disability Casemix Scale (LDCS) (Pendaries 1997) and the Family Support Scale (Dunst et al., 1984). A set of questions were also developed based on the Client Receipt Services Inventory (CRSI) (Beecham 1995).

General Health Questionnaire

The General Health Questionnaire (GHQ-12) is a brief 12-item self-report measure that screens for anxiety and depression over the previous few weeks in nonclinical settings (Goldberg and Williams 1988). The scale has been previously used with family carers of people with intellectual disability (Emerson et al. 2004; Grant et al. 2013) and has also been used in an Irish context to measure the prevalence of

psychological distress among the general public (Tedstone Doherty et al. 2008) and among formal carers working within institutional settings (Drennan et al. 2012). Responses range from 'not at all' to 'much more than usual'. Higher scores indicate higher levels of psychological distress (Goldberg et al., 1997). Using a binary format (0, 0, 1, 1), scores of 4 or above identifies persons experiencing psychological distress. The GHQ-12 has excellent psychometric properties and has been used extensively.

Social Connectedness Scale-Revised

The Social Connectedness Scale-Revised (SCS-R) comprises 20 questions and assesses a psychological sense of belonging or connectedness between the self and other people, including friends and society (Lee, Draper and Lee 2001). Ten items are worded positively and ten items are worded negatively. The negatively presented questions are reverse scored. Responses are then summed to give an overall total with possible scores ranging from 20 to 120. Higher scores are indicative of greater social connectedness. The scale demonstrates good internal reliability (Lee, Draper and Lee 2001).

Resilience Scale for Adults

The Resilience Scale for Adults (RSA) (Friborg et al. 2003) was first developed in Norway to examine intrapersonal and interpersonal protective factors that may influence how individuals manage and adapt to psychosocial adversities. Friborg et al. (2005) used a 33-item revised RSA scale which has a six factor structure: personal strength/perception of self, perception of future, social competence, structured style, family cohesion, social resources. Items are scored on a semantic differential scale with poled opposite responses. A number of items are reversed scored. All responses were summed; higher scores are indicative of higher resilience. A similar scale has been used with parents of children with intellectual disabilities (Grant et al. 2013) and Cronbach's alpha for the six subscales range from .73 to .83 (Hjemdal et al. 2006).

The Learning Disability Casemix Scale

The Learning Disability Casemix Scale (LDCS) (Pendaries 1997) is a 20-item parent report questionnaire, developed based on the similar conceptual groupings to the ICD-10 categories. The LDCS is popular as it is brief and is a respondent-completed measure that has minimal impact or burden upon the respondent. It has two subscales. The first subscale comprises 13 questions and rates the degree of severity of intellectual disability (mild, moderate, severe) and the second subscale comprises 7 items and rates the frequency of challenging behaviours. Scores are summed to give

an overall score of 0 to 60. Higher scores reflect greater levels of impairment and behavioural difficulties. Pendaries (1997) reported good validity for disability and fair for challenging behaviours.

Family Support Scale (FSS)

The Family Support Scale (FSS) (Dunst et al. 1984) measures the availability and perceived level of helpfulness of social supports in the previous three to six months. The scale comprises 18 questions, presented on a 5-point scale with responses ranging from (0) not at all helpful to (4) extremely helpful. If the source of social support is not available or does not apply, then respondents are asked to indicate this by responding 'non-applicable/not available'. The scale assesses the helpfulness of the nuclear family, informal kinship, social organisations, formal kinship, specialised professional services and general professional services. Dunst et al. (1984) demonstrates good reliability for the FSS in families of children with disabilities (internal consistency 0.77, and test–retest reliability 0.91). The scale has previously been used with family carers of people with autism and intellectual disabilities (Bromley et al. 2004; White and Hastings 2004; Weiss et al. 2013). In addition, respondents were asked to provide details of others who supported them by providing regular unpaid care to their relative with intellectual disability.

Client Services Receipt Inventory (CRSI)

The Client Services Receipt Inventory (CSRI) collects information on awareness and uptake of education, health and social services support services in the preceding six months (Beecham 1995). Based on the CSRI, a set of questions were developed for the purposes of this study to assess whether the care-recipient required the service in the preceding six months and whether they received it, and of those who received the service, respondents were asked whether they found the service helpful. The CSRI has previously been modified to make appropriate reference to children with autism (Bromley et al., 2004).

Phase 2: Telephone Interviews with Compound Carers

A semi-structured interview schedule was developed based on emerging key findings from Phase 1 of the study and on the published literature on compound carers. Questions were grouped using the following broad areas: the compound carer experience, managing and coping, impact of being a compound carer, services and supports, and opportunities and challenges. Examples of questions included: 'tell me how you became a compound carer?', 'how has being a compound carer impacted on you (personally, financially, and socially)?', 'what supports do you receive in your compound caregiving role?', 'as a compound carer, how do you think your role will

change, if at all, in the future?' Prompt questions and probing questions were used where necessary.

Fieldwork

Phase 1: Postal Survey of Family Carers

Cognitive interviews

In preparation for the postal survey, the penultimate draft of the questionnaire was pretested with a number of family carers of people with intellectual disability. Members of the Parents of Adults with Intellectual Disability (PAID) committee, at Family Carers Ireland, Smithfield engaged in cognitive interviewing in December 2015, which is a form of pretesting which ensures that the questionnaire is 'valid, relevant and usable' (Drennan 2013). It is a method that is increasingly being recognised as an approach that can systematically identify potential problems with survey questionnaires. One-to-one cognitive interviewing took place with four family carers, in which the length, language, accessibility and comprehensibility of the questions were assessed. The PAID committee meeting also provided an opportunity to pre-test the cover letters and participant information sheets. Feedback from the interviews were collated together with feedback and comments from members of the project's advisory panel and used to amend the final questionnaire.

Postal survey

The DSP distributed questionnaires through its postal service to a randomly selected sample of 600 carers on behalf of the research team. The DSP had entire responsibility for distribution of the questionnaires, the researchers did not have access to the names or contact details of carers registered on the DSP database. Similarly, the DSP did not have access to the completed questionnaires, which were returned directly to the research team. To ensure anonymity, no identification codes were used to track the questionnaires.

Data collection comprised three separate mail-outs. The first mail-out involved an initial pre-notice letter to all 600 carers, which was sent by the DSP, to inform carers that they would receive a questionnaire within a few days and would be invited to participate in the survey. The letter also emphasized that their participation was entirely voluntary and their decision to take part in the study would in no way affect their welfare payments or services. The second mail-out was received by carers within a week of the initial pre-notice letter and included a cover letter, a participant information sheet, a questionnaire, a stamped-addressed envelope and details of the compound carer element of the study. The third mail-out was sent to all 600 carers and consisted of a letter which thanked those carers who had already completed and returned their questionnaire, and invited those who had not yet responded, to do so.

Such follow-up reminders have proven effective in increasing response rates (Dillman et al., 2009).

Details of the survey were posted on the Family Carers Ireland's (formerly Carers Association) social media outlets (website, Facebook etc.). Care Alliance Ireland also featured the study on their Facebook page. This generated awareness of the study, assured carers of the legitimacy of the study, and encouraged carers who received a questionnaire to complete it and return it to the research team.

From a total of 600 questionnaires distributed to the randomly selected sample of family carers, 280 were returned to the research team. Of these, 247 were completed and deemed eligible for inclusion within the survey, yielding a 41% response rate.

Phase 2: Telephone Interviews with Compound Carers

Information relating to the compound carer element of the study was enclosed with the questionnaire package distributed in Phase 1. Respondents who responded 'yes' to the following question in the final section of the questionnaire were invited to read the relevant enclosed information labelled, 'The Compound Carer': 'apart from your relative to whom you provide full-time care, do you provide regular unpaid care to another person requiring care, due to a long-term illness, disability, frailty or other impairment (e.g. to an elderly parent, a sibling with a physical disability etc.)?'

A participant information sheet was supplied which provided additional information about this phase of the study, and outlined the voluntary nature of the telephone interview and the participant's right to confidentiality. The compound carers who were willing to be contacted by a member of the research team and participate in a telephone interview about their compound caregiving experiences, were asked to provide their contact details, sign a participant consent form and return it separately from their completed questionnaire using the additional stamped addressed envelope (SAE) provided. The reason for the additional SAE was to ensure that the carer's questionnaire was kept separate to their contact information and to ensure that anonymity would be maintained. In the first instance, male carers were contacted due to the underrepresentation of male carers in family caregiving (CSO 2012a), followed by female carers who were randomly selected according to geographical location. A member of the research team contacted the carers to confirm eligibility, informed consent and to arrange a time and day convenient to the carer to conduct the telephone interview. A total of 14 telephone interviews were conducted with carers about their compound caregiving experience. The duration of the interviews ranged between 40 and 75 minutes.

Data Analysis

Phase 1: Postal Survey of Family Carers

All of the survey data were coded and entered into Statistical Package for Social Sciences (SPSS) version 20 and cleaned. Appropriate descriptive statistical tests were conducted on the data and means, standard deviations, frequencies, percentages were presented. Comparisons between groups were made using chi-square tests on categorical data and independent sample t-tests and analysis of variance (ANOVA) on continuous variables. The Mann Whitney U test was used to look at associations between non-normally distributed data. Spearman's test of correlation was used to test for relationships between two variables with continuous data.

Phase 2: Telephone Interviews with Compound Carers

All audible compound carer interviews were transcribed verbatim and transcripts were imported into Nvivo 9.0 to support management and retrieval of data. Data from the telephone interviews with compound carers were analysed using thematic content analysis, using open coding to conceptualise the data and axial coding to connect resulting concepts (Creswell et al., 2013). The emerging themes and subthemes were presented.

Ethical Approval

Ethical approval to undertake a postal survey [Ref: LS-E-15-110-Lafferty] and to conduct telephone interviews [Ref: LS-15-67-Lafferty] with family carers of people with intellectual disabilities was granted by UCD's Human Research Ethics Committee [HREC].

Appendix 3 – Participant Information Sheet

UCD School of Nursing, Midwifery and Health Systems

UCD Health Sciences Centre,
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T +353 1 716 6488/6491
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Research Study: A Survey of Carers' Experiences of Caring for a Person with Intellectual Disability

Information Sheet

Introduction
This research study is being undertaken by researchers at University College Dublin (UCD), in partnership with Family Carers Ireland (formerly the Carers Association) and University of Ulster. With funding from the National Disability Authority (NDA), this research aims to explore carers' experiences of caregiving for a person with intellectual disability. The study is being led by Dr. Attracta Lafferty, Senior Researcher in UCD School of Nursing, Midwifery and Health Systems.

What is this study about?
This study is about carers' experiences of caring for a person with intellectual disability. We are particularly interested in learning about carers' ability to adapt to caregiving and the social and professional supports available to carers.

Why are we doing this study?
We want to understand more about the caregiving experience, including its impact on carers' health, carers' ability to manage and adapt to caregiving, and the support structures in place for carers caring for a person with intellectual disability. This information will help to inform the design and delivery of quality services for people with intellectual disability and their families.

What will the study involve?
This study will involve a survey of carers of a person with intellectual disability in Ireland. The Department of Social Protection (DSP) has kindly agreed to facilitate this survey by distributing questionnaires to a sample of carers on behalf of the research team. We would like to ask you to complete and return the questionnaire, using the stamped-addressed envelope provided, to the research team at UCD.

How was I selected for the study?
You have been randomly selected from a sample of carers who provide full-time care to a person with intellectual disability and are in receipt of Carer's Allowance. Please

be assured that no individual identifying information of any kind has been provided to UCD by the Department of Social Protection.

Do I have to take part?
Taking part in the survey is entirely voluntary. It is up to you to decide whether or not you would like to participate. Please be assured that your decision to participate or not to participate in the survey will in no way affect your welfare payments.

What will happen if I decide to take part in this research study?
If you decide to participate, you are required to complete the enclosed questionnaire and return it to the research team at UCD using the stamped-addressed envelope provided.

What will happen if I decide not to take part in this research study?
Nothing will happen. Please be assured that if you decide not to participate, your welfare payments will not be affected in any way.

Who will know if I take part?
No one will know. The survey is completely anonymous and confidential. There is no identification number or code of any kind on the questionnaire.

Are there risks involved in taking part in this study?
There are no known risks involved in the study; however, we recognise that some of the questions have the potential to be sensitive and may cause some upset. Should you experience upset, the Carers Association offers a confidential, friendly and supportive Freefone Care Line: **1800 24 07 24**. Lines are open Monday to Friday 9am-8pm; Saturday 10am-12noon.

What are the benefits involved in taking part in this study?
There are no direct benefits to you in taking part in the study; however all of the information gathered will be used to inform decisions by service providers and policy makers that will affect family carers' of a person with intellectual disability living in Ireland.

What will happen to the information from this research study?
All of the information collected from the survey will be entered into a dataset and analysed and the findings will be written up into a report which will be available from the NDA website (www.nda.ie), in summer 2016. Findings may also be made available in other formats such as summary reports, scientific papers in academic journals and presentations given at conferences.

Contact details
If you have any questions or if you would like further information, please contact:

Dr. Attracta Lafferty
UCD School of Nursing, Midwifery and Health Systems
UCD Health Science Centre
University College Dublin, Belfield, Dublin 4
E-Mail: familycarersID@ucd.ie Tel: + 353 (0)1 716 6468

Appendix 4 – Participant Consent Form: The 'Compound Carer'

Do you have caregiving responsibilities, other than those associated with the care you provide to a person with intellectual disability for whom you receive a carer's allowance? For example, do you **ALSO** provide regular unpaid care to another dependent person? This might include care to an elderly mother or father, mother-in-law, father-in-law, spouse/partner, sister, brother, aunt, uncle, friend, neigbour, and/or children under 18 years.

If yes, we would be interested in talking to you about your caregiving experience. Please provide your contact details below and return this sheet using the stamped addressed envelope labelled 'The Compound Carer'. **This should be returned separately from your questionnaire to ensure that your responses are kept confidential.** A UCD researcher will then call you to arrange a telephone interview on a day and at a time convenient for you.

We appreciate you taking time to return your contact details and for agreeing to take part in a telephone interview about your caregiving experience. The study findings will be important in informing services and supports for 'Tthe Compound Carer'.

	Please tick
• I am happy to have a UCD researcher contact me to arrange a telephone interview to discuss my experience of being a 'Compound Carer'; that is caring for a person with intellectual disability while also providing care (for 4 hours or more a week) to another person in need of care.	☐
• I understand that everything will be confidential and that my participation in the study is entirely voluntary and I can withdraw at any stage without giving a reason.	☐
• I agree to have the interview audio-recorded.	☐

NAME: _____

ADDRESS: _____

_____

TELEPHONE/MOBILE NUMBER: _____

SIGNATURE:_____

Please complete and return this sheet using the stamped addressed envelope labelled: 'The Compound Carer'.

Contact details for further information:

If you have any questions or if you would like more information, then please contact:

Dr Attracta Lafferty, Research Unit, UCD School of Nursing, Midwifery and Health Systems, UCD Health Science Centre, University College Dublin, Belfield, Dublin 4. E-Mail: attracta.lafferty@ucd.ie Tel: + 353 (0)1 716 6565

Appendix 5 – Interview Schedule

Project: Family Carers' Experiences of Caring for a Person with Intellectual Disability-
Part 2- 'The Compound Carer'

Interview Schedule – Telephone interviews

NOTE: 'A compound carer' is a person who provides care to more than one person.
These questions should be used as a guide only.
Please ensure process consent is sought throughout.

Introduction
The researcher introduces him/herself
Read aloud the Participant Information leaflet and address any questions
Remind the participant of his/her rights to withdraw at any stage and to confidentiality
Ensure that the participant is happy to have the interview audio-recorded.

Prompt questions will also be used to elicit deeper understandings throughout the interview.
Can you say a little more about that?
Can you give some examples?
Are there any other comments on that?

Examples of questions
Q1. Can you begin by telling me about how you came to be a 'compound carer'?
Q2. Can you tell me about your experience of being a 'compound carer'?
- How long have you been providing care?
- What is your relationship to the individuals to whom you provide?
- What is the nature of the care you provide e.g. with ADLs and IADLs etc.?
- Have you ever received training to support you with this type of care?
- How many live in your household/Do others provide help and support?

Q3. How do you balance your caregiving responsibilities?
Q4. What are the most challenging aspects, if any, of being a 'compound carer'?
Q5. How do you prioritize your caregiving responsibilities?
Q6. What are the most rewarding aspects, if any, of being a 'compound carer'?
Q7. How has being a 'compound carer' impacted on you (personally, financially, socially)?
Q8. What services/help do you receive to support you in your caregiving role?
Q9. Have you plans for the future care of the individuals to whom you provide care?
Q10. If it was possible, is there anything you would change about your caregiving circumstances?
Q11. Do you find that you often have competing caregiving demands, and if so, how do you deal with these?
Q12. Is there anything else you would like to say?

Ending the interview
Thank the participant for their time.
Provide the participant with the researcher's contact details and if relevant, support group numbers.